

# Evidence-Informed Health Policy: Using Research to Make Health Systems Healthier

Report from Kunnskapssenteret (Norwegian Knowledge Centre for the Health Services)

No 1-2008

A Multimethod Study



 **kunnskapssenteret**  
Norwegian Knowledge Centre for the Health Services

**Background:** • Over the past two years there has been a great deal of international discussion about how to harness health research more effectively in order to achieve the United Nations' Millennium Development Goals as well as other national health goals in low- and middle-income countries. • Our objective was to identify organisations around the world, and especially in low- and middle-income countries, that are in some way successful or innovative in supporting the use of research evidence in the development of clinical practice guidelines, health technology assessments, and health policy, and to describe their experiences.

**Key messages from the report:** • The study presents **seven main implications** for those establishing or administering organisations to produce clinical practice guidelines or health technology assessments, or organisations to support the use of research evidence in developing health policy: • 1. Collaborate with other organisations • 2. Establish strong links with policymakers and involve stakeholders in the work • 3. Be independent and manage conflicts of interest among those involved in the work • 4. Build capacity among those working in the

(continued)

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*(continued from page one)* organisation • 5. Use good methods and be transparent in the work

- 6. Start small, have a clear audience and scope, and address important questions
- 7. Be attentive to implementation considerations even if implementation is not a remit.

• The study presents **four main implications** for the World Health Organisation and other international organisations:

- 1. Support collaborations among organisations
- 2. Support local adaptation efforts
- 3. Mobilize support
- 4. Create knowledge-related global public goods, including methods and evidence syntheses.

**Client:** The report is prepared for the WHO Advisory Committee on Health Research.

- Links to a **Video Documentary Series** about the cases described in the study are found in the appendix, page 104.

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Norwegian Knowledge Centre for the Health Services  
Oslo, January 2008

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# Evidence-Informed Health Policy:

## Using Research to Make Health Systems Healthier

**A review of organisations that support the use of research evidence in developing guidelines, technology assessments, and health policy**

**Prepared for the WHO Advisory Committee on Health Research**

**A Final Report and Video Documentary Series**

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### CONFLICTS OF INTEREST

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ADO and EP are employed by the Norwegian Knowledge Centre for the Health Services, which was included in the survey. ADO is a member of the WHO Advisory Committee on Health Research. JNL is President of the PAHO/WHO Advisory Committee on Health Research and a member of the Scientific and Technical Advisory Committee of the Alliance for Health Policy and Systems Research, which is co-sponsored by and housed within WHO.



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## Key messages

The study's seven main implications for those establishing or administering organisations to produce clinical practice guidelines or health technology assessments or organisations to support the use of research evidence in developing health policy include:

1. Collaborate with other organisations
2. Establish strong links with policymakers and involve stakeholders in the work
3. Be independent and manage conflicts of interest among those involved in the work
4. Build capacity among those working in the organisation
5. Use good methods and be transparent in the work
6. Start small, have a clear audience and scope, and address important questions
7. Be attentive to implementation considerations even if implementation is not a remit

The study's four main implications for the World Health Organisation and other international organisations include:

1. Support collaborations among organisations
2. Support local adaptation efforts
3. Mobilize support
4. Create knowledge-related global public goods, including methods and evidence syntheses

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# Executive summary

## BACKGROUND

Over the past several years there has been a great deal of international discussion about how to harness health research more effectively to achieve the United Nations' Millennium Development Goals (MDGs) as well as other national health goals in low- and middle-income countries (LMICs). In November 2004, country delegations at the Ministerial Summit on Health Research held in Mexico City backed calls for establishing mechanisms to support the use of research evidence in policy and practice, as did the World Health Assembly in May 2005 when it approved a resolution arising from the Mexico Summit. We sought to inform deliberations about next steps by identifying organisations around the world, and especially in LMICs, which are in some way successful or innovative in supporting the use of research evidence in the development of clinical practice guidelines (CPGs), health technology assessments (HTAs), and health policy, and by describing their experiences.

## METHODS

We convened a project reference group, which provided feedback on our approach and materials. We undertook the project in three phases -- 1) a survey, 2) telephone interviews, and 3) case descriptions that drew on site visits -- and in each of the second and third phases we focused on a purposive sample of those involved in the previous phase. We drew on many people and organisations around the world to generate a list of organisations to survey. We modified a questionnaire that had been developed originally by the AGREE collaboration, adapted one version of the questionnaire for organisations producing CPGs and HTAs and another for organisations supporting the use of research evidence in developing health policy (government support units, or GSUs), piloted both versions of the questionnaire, and made a small number of final modifications to both versions of the questionnaire. We sent the questionnaire by email to 176 organisations and followed up periodically with non-responders by email and telephone. We then purposively sampled 25 organisations from among those who responded to the survey. We developed and piloted an interview schedule and conducted interviews by telephone with the director of each organisation. We then purposively sampled eight cases of one or more organisations bridging research and policy from among the cases described in the telephone interviews and (once) other cases with which we were familiar. We developed and piloted a case study data-collection protocol and conducted site visits for each

case. Data collection included interviews with 51 key informants and a review of publicly available documents. We conducted simple descriptive statistics using the survey data and we analysed the written survey responses, telephone interviews, in-person interviews, and documents using a constant comparative method of analysis. We produced a video documentary about each case study.

## **RESULTS**

The seven main recommendations that emerged from the advice offered in the telephone interviews provided a remarkably clear way to organise the principal findings and their implications for other organisations.

### **1. Collaborate with other organisations**

This advice was reinforced by: 1) the (quantitative) survey finding that more than half of the organisations (and particularly HTA organisations) reported that examples from other countries were helpful in establishing their organisation; 2) the (qualitative) survey finding that many organisations producing CPGs or HTAs conducted a focused review of one particular organisation that they then emulated or a broad review of a variety of organisational models; 3) the (qualitative) survey finding that the advice that was most commonly offered by organisations producing CPGs, HTAs or both was to seek support from similar existing organisations or networks, whether through informal interactions, study tours, mentoring relationships, twinning, partnerships or network memberships; 4) the (qualitative) survey finding that working within national networks and, more generally, collaborating rather than competing with other bodies, was a commonly cited strength in how GSUs are organised; and 5) the case descriptions finding that one of the two types of advice offered to other organisations was to learn from other organisations.

### **2. Establish strong links with policymakers and involve stakeholders in the work**

This advice was reinforced by: 1) the (quantitative) survey finding that a high proportion (88%) of GSUs involved target users in the selection of topics or the services undertaken; 2) the telephone interview finding that, while informal relationships with policymakers were identified more frequently as important by GSUs than by organisations producing CPGs, HTAs or both, nearly all of the organisations reported using personal communications with decision-makers, particularly policymakers; 3) the telephone interview finding that organisations both within and outside government viewed their close links with policymakers as a strength; 4) the case descriptions finding that the existence of a strong relationship between researchers and policymakers was repeatedly cited as one of two key organisational strengths; although this strength brought with it a related challenge, namely the need to manage the conflicts of interest that can emerge in any close relationship between researchers and policymakers.

### **3. Be independent and manage conflicts of interest among those involved in the work**

This advice was reinforced by: 1) the (qualitative) survey finding that independence is by far the most commonly cited strength in how organisations producing CPGs and HTAs are organised; and 2) the case descriptions finding that the presence of conflicts of interest was repeatedly cited as one of two key organisational weaknesses.

#### **4. Build capacity among those working in the organisation**

This advice was reinforced by: 1) the quantitative survey finding that most organisations have a small number of full-time equivalent (FTE) staff; 2) and the case descriptions finding that developing capacity among and retaining skilled staff and collaborators was one of their two frequently offered types of advice.

#### **5. Use good methods and be transparent in the work**

This advice was reinforced by: 1) the (quantitative) survey finding that between 84% and 100% of organisations reported providing panels with or using systematic reviews; 2) the (qualitative) survey finding that an evidence-based approach is the most commonly cited strength of the methods used by organisations that produce CPGs and HTAs; 3) the telephone interview finding that using rigorous methods that are systematic and transparent (sometimes shortened to “being evidence based”) was the most commonly cited strength among all organisations; and 4) the case descriptions finding that the use of an evidence-based approach was one of two organisational strengths that were repeatedly cited. However, all but one of the organisations producing CPGs, HTAs or both used informal methods for setting priorities; relatively few organisations producing CPGs and HTAs convened groups to develop CPGs or HTAs, took equity considerations into account or had established a process for addressing conflicts of interest; and GSUs were less likely to have a manual that described the methods they use and to conduct or use systematic reviews and more likely to report using non-systematic methods to review the literature. In addition, using systematic and transparent methods brought with it a related challenge, namely the time-consuming nature of an evidence-based approach.

#### **6. Start small, have a clear audience and scope, and address important questions**

This finding was reinforced by: 1) the (qualitative) survey finding that the most commonly cited weakness in how these organisations are organised is a lack of resources, both financial and human; 2) the (qualitative) survey finding that the most commonly cited weakness of the methods used by organisations that produce CPGs and HTAs was their time-consuming and labour-intensive nature; 3) the (qualitative) survey finding that GSUs advised others establishing a similar organisation to attend to the need for secure funding; 4) the telephone interview finding that the weakness noted by most of the CPG- and HTA-producing organisations was inadequate resources, more specifically insufficient numbers of skilled staff and time, together with using labour- and time-intensive processes that limit the number and quality of CPGs and HTAs that can be produced and updated; and 5) the case descriptions finding that a lack of resources was repeatedly cited as one of two organisational weaknesses.

#### **7. Be attentive to implementation considerations even if implementation is not a remit**

This advice is reinforced by: 1) the (quantitative) survey finding that less than half of all organisations provided a summary of take-home messages in their products; 2) the (quantitative) survey finding that between one half and two thirds of organisations do not collect data systematically about uptake; 3) the (qualitative) survey finding that the most commonly cited weaknesses of CPG- and HTA-producing organisations’ outputs are the lack of dissemination and implementation strategies for the outputs and the lack of monitoring and evaluation of impact; 4) the telephone interview finding that most organisations argued that it is the clients who requested a CPG or HTA, the minister of

health or more generally the department of health who is responsible for implementing recommendations or policy decisions; 5) the telephone interview finding that all types of organisations tended to focus largely on weaknesses in implementation when asked about both strengths and weaknesses, with few exceptions; and 6) the telephone interview finding that most of the examples of success among organisations producing CPGs, HTAs or both were occasions where there was a perception that clinicians adhered to the organisation's recommendations or policymakers based their decisions (at least in part) on the work of the organisation.

## **DISCUSSION**

The study has six main strengths: 1) we examined the views and experiences of those familiar with three types of organisations that support evidence-informed policymaking, not just one of the two types of organisations previously studied (i.e., we surveyed GSUs as well as CPG- and HTA-producing organisations, we interviewed roughly equal numbers of CPG- and HTA-producing organisations and GSUs, and the majority of case descriptions were GSUs); 2) we achieved both breadth (through a survey) and depth (through telephone interviews with directors and then case descriptions that drew both on interviews with a range of staff, advocates and critics and on documentary analyses) in our examination of their views and experiences; 3) we drew on a regionally diverse project reference group to ensure that our draft protocol, study population, questionnaire, interview schedule, and case study data-collection protocol were fit for purpose; 4) we adapted a widely used questionnaire and achieved a high response rate with our survey (86%); 5) we used explicit sampling criteria to identify particularly successful or innovative groups for more in-depth study through telephone interviews and case descriptions, no organisation declined to participate in the telephone interviews, and only one individual declined to participate in the interviews conducted as part of the site visits; and 6) we employed a variety of independent checks on the credibility of our thematic analyses of the written questionnaire responses and the telephone interview and case study data. The study has two main weaknesses: 1) despite significant efforts to identify organisations in low- and middle-income countries, just over half (54%) of the organisations we surveyed and just under half (48%) of the organisations we interviewed were drawn from high-income countries; and 2) despite efforts to ask questions in neutral ways, many organisations may have been motivated by a desire to tell us what they thought we wanted to hear (i.e., there may be a social desirability bias in their responses).

## **CONCLUSIONS**

Participants regard an evidence-based approach as the greatest strength in the way these organisations conduct their work. They see the time-consuming nature of an evidence-based approach as the greatest weakness. They view relationships between researchers and policymakers as highly desirable, but there appears to be little awareness of the nature of potential tensions that can arise and how to manage or resolve them. A lack of resources, both financial and human, poses a challenge in many organisations. Conflicts of interest are seen as a critical issue. Multi-disciplinary teams and international networks are seen as highly desirable, and there is a strong perceived need for coordination at an international level to avoid duplication of processes. Little effort is put into dissemination and implementation activities in relationship to the efforts that are focused

on producing evidence-based materials. Negligible efforts are put into communicating evidence to the wider public, via the mass media, and beyond stakeholder constituencies.

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## Abbreviations

AGREE	Appraisal of Guidelines for Research and Evaluation
CPG	Clinical practice guideline
EBM	Evidence-based medicine
EUNetHTA	European Network for Health Technology Assessment
EuroScan	European Information Network on New and Changing Health Technologies
EVIPNet	Evidence-Informed Policy Network
FTE	Full-time equivalent
GIN	Guidelines International Network
GP	General practitioner
GRADE	Grading of Recommendations Assessment, Development and Evaluation
GSU	Government support unit
HEN	Health Evidence Network
HTA	Health technology assessment
HTAi	Health Technology Assessment International
INAHTA	International Network of Agencies for Health Technology Assessment
INCLIN	International Clinical Epidemiology Network
LMIC	Low and middle-income country
MI	Myocardial infarction
REACH	Regional East African Community Health
TA	Technology assessment
WHO	World Health Organization

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# Report

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## BACKGROUND

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Over the past two years there has been a great deal of international discussion about how to harness health research more effectively in order to achieve the United Nations' Millennium Development Goals as well as other national health goals in low- and middle-income countries (LMICs). One important focus in this discussion has been the call to develop mechanisms to support the use of research evidence in developing clinical practice guidelines, health technology assessments, and health policy. The chapter on linking research to action in the World Report on Knowledge for Better Health that was released by the World Health Organisation (WHO) in early November 2004 provided a framework for appreciating the diversity and complementarities of many of these mechanisms [WHO 2004a]. The health ministers and heads of national delegations from 58 countries who participated in the Ministerial Summit on Health Research that was held in Mexico City in November 2004 reiterated the call for developing such support mechanisms) [WHO 2004b].

At the World Health Assembly that was held in Geneva in May 2005, these debates culminated in the passage of a two-part resolution that established specific accountabilities for developing mechanisms to support the use of research evidence in developing health policy [WHA 2005]. The first part of the resolution called on WHO member states to “establish or strengthen mechanisms to transfer knowledge in support of evidence-based public health and health-care delivery systems, and evidence-based health-related policies.” The second part of the resolution called on WHO's Director-General to “assist in the development of more effective mechanisms to bridge the divide between ways in which knowledge is generated and ways in which it is used, including the transformation of health-research findings into policy and practice.”

Related to these resolutions, WHO asked the Advisory Committee on Health Research (ACHR) for advice on ways in which WHO can improve the use of research evidence in the development of recommendations, guidelines and policies. The ACHR established a subcommittee to collect background documentation and consult widely among WHO staff, international experts and end users of WHO recommendations to inform this ad-



vice. This report was prepared as part of the background documentation to inform ACHR's advice to WHO.

Organisations have already been established in many countries and internationally to support the use of research evidence in developing health policy. These include organisations that produce clinical practice guidelines (CPG), health technology assessment (HTA) agencies, and organisations that directly support the use of research evidence in developing health policy on an international, national, and state or provincial level (hereafter called government support units, or GSUs). While there are important differences among these organisations, there are also many commonalities and opportunities for existing and new organisations to learn from this collective experience. A review of this experience can reduce the need to 'reinvent the wheel' and inform decisions about how best to organise support for evidence-informed health policy development processes.

Our objective was to identify organisations around the world, and especially in LMICs, that are in some way successful or innovative in supporting the use of research evidence in the development of CPGs, HTAs and health policy, and to describe their experiences. We pursued this objective in a three-phase study. First, we surveyed a senior staff member (the director or his or her nominee) of CPG-producing organisations, HTA agencies, and GSUs about their history, processes, and perceived strengths and weaknesses. Second, we interviewed the senior staff member of a purposively sampled sub-group of these three types of organisations, with an emphasis on those organisations that were particularly successful or innovative. Third, we undertook case studies (with site visits) of one or more organisations bridging research and policy from among the cases described in the telephone interviews and (once) other cases with which we were familiar, again with an emphasis on those organisations that were particularly successful or innovative.

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## METHODS

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In order to maintain a focus on LMICs, we convened a project reference group that drew on two or three individuals who were from or who are very knowledgeable about each of Africa, Asia, and Latin America, as well as individuals from North America, Europe (including a representative from the project funder), and WHO (including members of the Advisory Committee on Health Research) (Appendix 1). Collectively the reference group provided many perspectives on the three types of organisations under study and on potential country- or region-level differences in the opportunities and challenges confronting these organisations. The reference group provided feedback on our draft protocol, study population, questionnaire, interview schedule, and case study protocol.

### PHASE 1: SURVEY

#### *Study population*

Eligible CPG-producing organisations, HTA agencies, and GSUs had to perform at least one of the following functions (or a closely related function): 1) produce systematic reviews, HTAs or other types of syntheses of research evidence in response to requests from decision-makers (i.e., clinicians, managers, and policymakers); 2) identify and contextualise research evidence in response to requests from decision-makers; and/or 3)

plan, commission or carry out evaluations of health policies in response to requests from decision-makers. The GSUs could include units located within a health system, government or international organisation, units hosted within a university or other research-intensive organisation, and independent units with a mandate to directly support evidence-informed health policy (including health care policy, public health policy, and healthy public policy). We excluded organisations that receive core funding from industry or that only produce or provide health or healthcare utilization data.

While we included all eligible organisations from LMICs that were identified by any of the people we contacted, for high-income countries we included: 1) established CPG-producing organisations that are members of the Guidelines International Network (GIN) and selected other organisations that are known to produce CPGs in particularly innovative or successful ways; 2) established HTA agencies that are members of the International Network of Agencies for Health Technology Assessment (INAHTA) and select other HTA agencies that are known to produce HTAs in particularly innovative or successful ways; and 3) any units that directly support the use of research evidence in developing health policy. We included organisations that were considered by ourselves or their nominators to be particularly innovative or successful based on recommendations of those we contacted and our own knowledge. No explicit criteria were used in making these judgements.

We drew on members of both formal and informal international networks to identify particularly innovative or successful CPG-producing organisations and HTA agencies and to identify GSUs. The formal networks included the Appraisal of Guidelines for Research and Evaluation (AGREE) collaboration, the Cochrane Collaboration, GIN, GRADE Working Group, International Clinical Epidemiology Network (INCLIN) Knowledge Management Program, and INAHTA. The informal networks included our project reference group, staff at WHO headquarters and regional offices, and personal networks.

### ***Survey development and administration***

We drew on a questionnaire developed and used by the AGREE collaboration [Burgers 2003a] and we modified questions as necessary given our focus on LMICs. The questions covered seven domains: 1) organisation; 2) why and how the organisation was established; 3) focus; 4) people involved; 5) methodology employed; 6) products and implementation; and 7) evaluation and update procedures (Appendices 2 and 3). We also included a final group of additional questions. About two fifths of the questions were open-ended. Two of the questions were changed for the version of the questionnaire administered to GSUs; this questionnaire had 48 questions instead of 49. We piloted the questionnaire with three organisations in each category (and received responses from five organisations) in April 2005. No changes were made in the questionnaires following based on the pilot.

We sent the questionnaire by email to the director (or another appropriate person) of each eligible organisation with three options for responding: by answering questions in the body of our email message and returning it; by answering questions in a Word version of our questionnaire attached to our e-mail message and returning it; or by printing a PDF version of our questionnaire, completing it by hand, and mailing it. We sent three reminders if we did not receive a response up until October 2005. We used additional

mechanisms to increase the response rate, including an endorsement letter and personal contacts [Edwards 2003].

### ***Data management and analysis***

Quantitative data were entered manually and summarized using simple descriptive statistics. Written comments were grouped by question and one member of the team (RM) identified themes using a constant comparative method of analysis, and the findings were then independently reviewed by two members of the research team (AO and JL) and disagreements resolved by consensus.

## **PHASE 2: TELEPHONE INTERVIEWS**

### ***Study sample***

We purposively sampled organisations from among those who completed a questionnaire based on the following three criteria: 1) able to provide rich descriptions of their processes and lessons learned; 2) particularly successful or innovative in one or more of the seven domains covered in the questionnaire; and 3) influential over time within their own jurisdiction in bridging research and policy or influential in the establishment or evolution of similar organisations in other jurisdictions. The first criterion was applied by one member of the study team (RM) based on his reading of the completed questionnaires. The second and third criteria were applied by three members of the study team (AO, JNL, RM) based on their knowledge and experience with these types of organisations.

### ***Interview guide development and interviewing***

We developed the first draft of the semi-structured interview guide in parallel with the questionnaire as a mechanism to augment questions that could not or could only partially be addressed in the questionnaire. These 18 core questions were followed by organisation-specific questions that arose based on responses provided in the questionnaire and by cross-cutting questions that addressed particular themes or hypotheses that emerged from the survey or earlier telephone interviews (Appendix 4). One member of the study team (RM) piloted the interview guide with four organisations, at least one of which was from each of the three categories. No significant changes were made after piloting. A request for an interview was sent by email to the director (or another appropriate person) of each eligible organisation and a date and time was set either through email or telephone calls. The same member of the study team (RM) either conducted the interviews or supervised a trained interviewer who conducted the interviews (JL). Notes of all interviews were taken simultaneously. All interviews were audio-taped but only select interview segments were transcribed verbatim.

### ***Data management and analysis***

Detailed summaries of each interview were prepared by one member of the study team (RM) using both the audio-tapes and notes taken during the interviews and these detailed summaries were subsequently analyzed independently by two members of the study team (AO, RM) with disagreements resolved by consensus. The detailed summaries were organised by question. During the analysis the detailed summaries were first read separately and supplemented, where necessary, by listening to part or all of the corresponding audio-tapes. Themes were identified using a constant comparative method of

analysis. Then question- and theme-specific groupings of the detailed summaries were developed and read, and the themes were modified or amplified. Illustrative quotations were identified to supplement the narrative description of the themes.

### **PHASE 3: CASE STUDIES**

#### ***Study sample***

We purposively sampled eight cases of one or more organisations bridging research and policy from among the cases described in the telephone interviews and (once) other cases with which we were familiar, using the same three criteria used for the telephone interviews as well as four additional criteria: 1) coverage of both low- and middle-income countries, with a particular emphasis on low-income countries; 2) coverage of all major regions, with a particular emphasis on Africa, Asia, and Latin America; 3) coverage of the three categories of organisations, with a particular emphasis on GSUs; and 4) coverage of the themes that emerged from the questionnaires and telephone interviews. One case was selected based on the knowledge of study investigators, rather than the survey or telephone interviews - the Regional East African Community Health (REACH) Policy Initiative, which is currently in the resource-mobilization phase in its development. One member of the study team (RM) again applied the first criterion (i.e., able to provide rich descriptions of lessons learned) and three members of the study team (AO, JNL, RM) applied the remaining criteria, first independently and then as a group.

We decided during the course of the project to make short video documentaries about each site visit (case study), and a cameraperson / editor / technical producer (Miranda Burne) was hired to work with a member of the study team (RM) on this series (Appendix 5). Advantages of the video documentaries are that they:

- let people describe in their own words what they are doing and the audience can hear this and see them and the context in which they work;
- are entertaining and people enjoy them, thus enhancing their impact;
- can include conflicting viewpoints that can be a good starting point for discussion and debate;
- can highlight different issues that are of broad relevance, such as explicit versus implicit rationing, tensions between researchers and policy makers working together, and conflicts of interest;
- provide people an opportunity and stimulus to reflect about how they are doing things; and
- can be helpful in one-on-one meetings with decision makers to get across concepts and generate enthusiasm.

#### ***Case study data-collection protocol development and site visits***

We developed the first draft of the case study data-collection protocol after having conducted preliminary analyses of both the questionnaires and telephone interviews. The protocol included the types of individuals with whom interviews were to be requested, the interview guide, and the sorts of images to be captured in the video documentaries. The types of individuals with whom interviews were requested included 1-2 staff members other than the director of the organisation, an advocate of the organisation, and at least one critic of the organisation. Publicly available documents pertinent to the site visits were also requested and gathered.

The interview guide included four core questions (strengths, weaknesses, advice for others, and suggestions for WHO) that were followed by organisation-specific questions that arose based on responses provided in the questionnaire and telephone interviews and by cross-cutting questions that addressed particular themes or hypotheses that emerged from the survey or telephone interviews. We piloted the interview guide with one organisation chosen for a site visit. No significant changes were made after piloting. One member of the study team (RM) and the cameraperson / editor (MB) conducted all the site visits. A request to host a site visit was sent by email to the director of each selected organisation (or other staff) and the arrangements were made through e-mail or telephone calls. Most interviews were video-taped but only select interview segments were transcribed verbatim. For a small number of interviews with people in the field, only notes were taken. The list of images to be captured included city panoramas, the buildings in which the organisation is located, the reception desk, key interviewees, and other images to help illustrate the narrative of each case study.

### ***Data management and analysis***

Detailed summaries of each case study were prepared by one member of the study team (RM) using the videotapes, notes taken during the interviews, notes taken during the visit, and documents obtained during the visit. The detailed summaries were organised by question and any additional points raised during the visits were grouped together at the end of each summary. Themes were identified in both the full interviews and the answers to the four key questions, using a constant comparative method of analysis. Then question- and theme-specific groupings of the detailed summaries were read and the themes modified or amplified. Illustrative quotations were identified to supplement the narrative descriptions. We then produced a brief (1-2 page) case description for each organisation visited. One member of the study team (RM) and a cameraperson / editor (MB) produced and edited short video documentaries for each case study.

No sensitive data were collected and none of the participants requested confidentiality. The purpose of the survey was explained in the survey instrument (Appendices 2 and 3), participation was voluntary, and return of a completed survey indicated consent to our use of the collected information in this study. Verbal consent was obtained for the telephone interviews and face-to-face interviews as well as their recording.

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## **RESULTS**

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### **PHASE 1: SURVEY – QUANTITATIVE RESULTS**

We sent 176 questionnaires, and 152 (or 86%) completed questionnaires were returned between April and October 2005. Ninety-five organisations produce CPGs, HTAs or both and 57 units support government policymaking (Table 1). Twenty-nine organisations were identified through the Guidelines International Network (GIN) membership list, 26 through the International Network of Agencies for Health Technology Assessment (INAHTA), 14 through INCLIN, and 82 through personal contacts (including responses to the last question in the questionnaire that asked about other organisations) (Table 1).

Forty-nine of the 57 units supporting government policymaking were identified through personal contacts.

Although we intentionally sought out organisations in LMIC, 56% (85/152) were from high-income countries, 13% (19) from upper middle-income countries, 24% (36) from lower middle-income countries and 5% (8) from low-income countries. Over half the organisations (54%) that produced CPGs and HTAs were identified through GIN and INAHTA (51/95) and 68% (65) were from high-income countries compared to 35% (20/57) of units supporting government policymaking. Although we aimed to identify organisations throughout the world, the included organisations were not spread evenly across different regions. Sixty-seven percent (64/95) of the organisations that produce CPGs and HTAs were located in Western Europe (40), North America (17), Australia and New Zealand (7), compared with 33% of units supporting government policymaking (19/57). We identified few organisations in Eastern Europe (1 organisation), India (2), the Middle East (3) or China (4) that met our inclusion criteria, and only four international organisations were included (COHRED; INCLIN; Health Evidence Network (HEN), WHO European Region; Essential Drugs and Medicine (EDM) Department, WHO).

### ***Organisation and establishment***

A high proportion of organisations that produce CPGs, HTAs or both also support government policymaking in other ways, whereas the reverse (GSUs producing CPGs or HTAs) was much less common (Table 2). Among the array of services undertaken in response to requests from public policymakers, GSUs are most likely to convene expert meetings to discuss available research (82%) and undertake short-term research projects (79%). Organisations that produce CPGs were often based in professional associations (45%) whereas organisations that produce HTAs or both CPGs and HTAs were often based in government agencies (63% and 49% respectively). GSUs were also often based in academic institutions (37%) and government agencies (39%). HTA organisations were particularly likely to receive funding from government sources (95%) whereas the other types of organisations did not have such a commonly shared revenue source. More than half of the organisations (and particularly HTA organisations) reported that examples from other countries were helpful in establishing their organisation.

### ***Age, budget and production profile***

The organisations' ages, budgets and production profiles varied dramatically (Table 3). The median age was 7-10 years depending on the type of organisation, however, one organisation was brand new and another had a 94-year history. The median annual budget was lowest for CPG-producing organisations and highest for HTA-producing organisations. The median number of CPGs or HTAs produced per year ranged from three to seven and the median time spent to produce a CPG or HTA ranged from 10-15 months.

### ***Focus***

Organisations producing CPGs were more often focused on health care (65-84%) than on public health (45%) or healthy public policy (26%) whereas GSUs were more focused on public health (88%) and to a lesser extent on primary healthcare (72%) and healthy public policy (67%) (Table 4). A high proportion of GSUs provided service on many facets of policy issues: characterizing problems (74%), identifying potential solutions (82%), fitting solutions into health systems (75%), and bringing about change in health systems (88%).

Organisations producing CPGs were more focused on physicians (100%) and to a lesser extent other types of healthcare providers (77%) as their target users, whereas HTA organisations were more focused on healthcare managers (95%) and public policymakers (100%). GSUs were most focused on public policymakers in health departments, followed by public policymakers in central agencies (77%), stakeholders (79%) and public policymakers in other departments (63%). A higher proportion of GSUs involved target users in the selection of topics or the services undertaken than CPG- or HTA-producing organisations.

### ***People involved in producing a product or delivering a service***

Most organisations have a small number of full-time equivalent (FTE) staff (Table 5). For example, more than half of organisations producing CPGs, HTAs or both have between one and five FTE staff. More than half of all organisations always involved an expert in information / library science and more than two thirds of CPG- and HTA-producing organisations always involved an expert in clinical epidemiology. More than half of all HTA organisations also always involved a health economist and (only if necessary) involved experts in biostatistics, other types of social scientists, and a consumer representative. More than two thirds of organisations producing CPGs or both CPGs and HTAs involve target users by inviting them to participate in the development group or to review the draft product. A higher proportion of GSUs than other types of organisations involve consumers in product development or service delivery. For example, 44% of GSUs invite consumers to participate in the development group and 54% survey their views/preferences. More than two thirds of organisations producing CPGs consider geographic balance in expert or target user selection, but a lower proportion of other types of organisations use this criterion.

### ***Methods used in producing a product or delivering a service***

Organisations draw on a wide variety of types of information (Table 6). More than four fifths (84-100%) of organisations reported providing panels with or using systematic reviews. Organisations producing CPGs, HTAs or both tended to use an explicit valuation process for the research evidence (89-97% prioritized evidence by its quality) but less often for outcomes (52-61% prioritized outcomes by their importance to those affected) and still less often for groups (0-26% prioritized groups by their importance to achieving equity objectives). GSUs tended to use a wide variety of explicit valuation processes but none with the frequency that organisations producing CPGs, HTAs or both prioritized evidence by its quality. A higher proportion of organisations producing CPGs, HTAs or both graded recommendations according to the quality of the evidence and/or the strength of the recommendation than used other methods to formulate recommendations. Roughly half of GSUs used each of subjective review, consensus, and grading to formulate recommendations. A higher proportion of organisations producing CPGs, HTAs or both explicitly assessed the quality of evidence in formulating recommendations than explicitly assessed the trade-offs between benefits and harms, costs or equity. Almost half of GSUs explicitly assessed equity in formulating recommendations. A higher proportion of organisations used internal review or external review by experts than other review processes.

### ***Products and implementation***

All or almost all organisations producing CPGs, HTAs or both produced a full version of their final product with references whereas only HTA organisations uniformly produced both the full version and an executive summary (Table 7). Less than half of all organisations provided a summary of take-home messages as part of their products. More than two thirds of organisations producing CPGs, HTAs or both posted to a website accessed by target users and more than two thirds of organisations producing HTAs or both CPGs and HTAs mailed or e-mailed products to target users. Only 14% of GSUs submitted products to any form of clearinghouse. More than half of organisations were involved in different strategies to develop the capacity of target users to acquire, assess and use their products or services. Almost two thirds of GSUs involved target users in an implementation group whereas lower proportions of other types of organisations involved target users in implementation through this or another approach.

### ***Evaluation and update procedures***

Between one half and two thirds of organisations do not collect data systematically about uptake and roughly the same proportions do not systematically evaluate their usefulness or impact in other ways (Table 8). A little over half (52%) of organisations producing CPGs update their products regularly whereas less than half (45%) update them irregularly. A higher proportion of other types of organisations update their products and services irregularly (49-63%) than regularly (11-37%).

## **PHASE 1: SURVEY – QUALITATIVE RESULTS – ORGANISATIONS PRODUCING CPGS AND HTAS**

### ***Organisation***

For organisations producing CPGs and HTAs the most common *formal* relationships are with government and parastatal agencies, professional bodies, and universities. The relationship with a government's health department is typically regarded as the most valuable; however, the reasons for this assessment can be quite diverse, including the health department's roles as a funder or as a principal target audience. Close relations with professional bodies are also commonly seen as valuable, typically because of their credibility with another target audience – clinicians. These organisations also have formal relationships with many international networks, including Guidelines International Network (GIN), Health Technology Assessment International (HTAi), and International Network of Agencies for Health Technology Assessment (INAHTA). Relationships with these networks can provide peer-to-peer information exchange. Relationships with industry or consumer groups are rarely cited as particularly important or valuable.

Independence is by far the most commonly cited strength in how these organisations are organised. Typical responses to the question about an organisation's main strength include: "financial and intellectual independence" and "freedom from government and industry influence." A lack of resources, both financial and human, is the most commonly cited weakness in how these organisations are organised. Financial resources are often inadequate or time-limited. Human resource limitations typically involve a lack of qualified staff (e.g., methodological experts) and volunteers (e.g., clinical experts) without significant conflicts of interest. A lack of resources can add significantly to the length of time it takes to produce a guideline or HTA, with some organisations citing a perception



that they are too slow to respond to health system challenges. Another, less commonly cited weakness was the lack of implementation strategies and evaluations.

### ***Establishment***

The question about what background documents or resources were helpful in establishing the organisation was variously interpreted as pertaining to the documents that led to the creation of the organisation, to the documents that informed their CPG- or HTA-development processes, and (as was the question's intent) to the documents that informed *how* the organisation was established. No documents were cited repeatedly as being particularly helpful in informing how the organisation was established, although many organisations conducted a focused review of one particular organisation that they then emulated or a broad review of a variety of organisational models.

Few individuals responded to the question about what other information would have been helpful in establishing the organisation and there was no clear pattern in the responses of those who did. Some organisations did note that information about other similar organisations' practical experiences may have been helpful in establishing the organisation (e.g., how to nurture a policy climate that supports evidence-based CPGs and HTAs, operational procedures for producing CPGs and HTAs, and time and resource estimates for producing CPGs and HTAs).

The advice that was most commonly offered to others establishing a similar organisation was to seek support from similar existing organisations or networks, whether through informal interactions, study tours, mentoring relationships, twinning, partnerships or network memberships. Other advice for those establishing new organisations ranged from being clear about what need the organisation will fill given existing local, national and international initiatives to ensuring independence (both in terms of the organisation itself and the individuals working in it) and establishing good relationships with key target audiences from the beginning.

### ***Methods used in producing a product or delivering a service***

Organisations tend to make decisions about which CPGs or HTAs to produce on the basis of explicit criteria such as disease burden, national priority area, and utilization, cost or safety profile (e.g., prescription drugs or technologies used in high volumes, at high cost or with safety concerns); input or requests from health policymakers, insurers, health system managers, clinicians, experts, and other stakeholders (through surveys and both formal and informal consultations); or both. For example, a professional body that produces guidelines used the following explicit criteria:

- conditions for which the diagnosis and management of the disease could be significantly improved by a change in practice;
- a body of published evidence exists on which to base the guideline;
- topic has wide variability in practice;
- topic is controversial;
- topic includes interventions that potentially have high economic cost;
- topic is of interest and importance to public health; and
- range of topics reflect the constituency of the professional body and cross over its various disciplines.

Some organisations have an explicit timetable for updating their CPGs and HTAs.

An evidence-based approach is the most commonly cited strength of the methods used by these organisations. In describing an evidence-based approach, survey respondents use terms such as systematic, explicit, transparent, rigorous, and reproducible. For example, one individual cited “to use an explicit and systematic methodology that can be reproducible” as the main strength of the methods they use. As another example, systematic reviews are cited as a strong protection against bias in the identification, selection, appraisal and synthesis of the research literature on which CPGs and HTAs are based. Involving stakeholders in the process also emerged as a frequently cited methodological strength, although the focus tended to be more on clinicians than on citizens or consumers. A much smaller number of organisations cited flexibility and grading the strength of recommendations as methodological strengths.

The most commonly cited weakness of the methods used by these organisations was their time-consuming and labour-intensive nature. This weakness was felt very acutely by many organisations because it left them vulnerable to assertions that they were slow and insufficiently responsive. Other cited weaknesses included the insufficient involvement of citizens / consumers and a lack of or low quality evidence on priority topics.

### ***Products***

The main strength of the organisations’ outputs was commonly seen as the brand recognition that was perceived to flow from the organisations’ evidence-based approach and, much less commonly, from their strict conflict-of-interest guidelines. This brand recognition was typically spoken of in terms of either credibility and trustworthiness or high standards and quality. Other less commonly cited strengths included outputs being available in many different formats (e.g., print and web-based, short summaries and full reports, and outputs written at different language levels) and outputs being timely, relevant to local needs, and locally applicable.

The most commonly cited weaknesses of the organisations’ outputs are the lack of dissemination and implementation strategies for the outputs and the lack of monitoring and evaluation of impact. Other weaknesses include a lack of user-friendly products and a lack of timeliness. One respondent reported “[w]e cannot produce enough new evidence in a timely fashion.” Another reported “[The] development process takes too long. Recommendations are in danger to be outdated by the time they are published.”

### ***Advocates and critics***

The organisations’ strongest advocates are the individuals, groups and organisations who have worked with the organisations (e.g., funders, heads of professional bodies, panel members, and researchers) or who have benefited from their outputs (e.g., health policymakers making technology funding decisions, health professionals making clinical decisions). While the reasons for their support vary, most advocates appear to value participating in the production of CPGs and HTAs or being able to draw on independent and timely high-quality and high-relevance CPGs and HTAs.

The most commonly cited critic of the organisations was the pharmaceutical industry and clinicians who are closely associated with them. More generally, a respondent from one organisation summed up the different types of critics quite succinctly: “[Critics] fall

into three groups: those who disagree with our conclusions; those who would like to have more rapid conclusions/recommendations from HTAs; and those who do not see the value of HTAs. These groups are not mutually exclusive!” Several organisations proudly cited people within their own organisation as their strongest critic. For example, a respondent from one organisation said that “the strongest critics are often our own staff. We foster a culture of self-examination and critique.”

### ***Role of WHO and other international organisations***

A question gauging views about WHO’s and other international organisations’ *current* role in developing guidelines and HTAs and helping policymakers to access and use research evidence did not reap a rich set of responses. Many organisations in high-income countries focused on the importance of international networks such as Guidelines International Network (GIN), Health Technology Assessment International (HTAi), and International Network of Agencies for Health Technology Assessment (INAHTA), whereas many organisations in low- and middle-income countries focused on WHO’s role more generally and not specifically in the domain of CPGs and HTAs.

A question about what role WHO and other international agencies *should* play produced a richer set of responses. The most commonly cited suggestions were that WHO and other international organisations play a facilitating role in coordination efforts (in order to avoid duplication) and in local adaptation efforts (in order to enhance local applicability). Other suggestions included: providing an “inventory of evidence” and disseminating it on a global scale; producing guidelines for guideline developers; and supporting networks that in turn support others working in this field. The following selected quotes illustrate some of the key suggestions.

“I’d also like to see better international collaborations that allow all of us to complement each other rather than so often having the reality or perception that we’re duplicating each other.”

“WHO has a key role in influencing practice worldwide. It may not be the best placed organisation for developing guidelines, but it could endorse guidelines developed by national programmes and/or encourage access [to] and use of evidence across countries. Many of the guidelines developed in ‘advanced’ countries would not be applicable to all countries. Therefore there is a need to adapt existing guidelines, or find ways for using evidence/teaching in less developed countries.”

“...promote information sharing on specific guidelines; encourage work on guideline or TA adaptation; encourage work on issues that may not be relevant to one single country but to a region; encourage networking, particularly to help eastern countries.”

WHO “can use its prestige to support right and systematic methods to develop guidelines.”

## **PHASE 1: SURVEY – QUALITATIVE RESULTS – GOVERNMENT SUPPORT UNITS**

There was a great deal more heterogeneity in the responses from the GSUs than in the responses from the organisations producing CPGs and HTAs.

### ***Organisation***

For GSUs the most common formal relationships are with government and the most valuable of these relationships typically with government departments of health. One respondent replied: “Arm[s] length relationship with the Ministry of Public Health is important, not too close to be dominated and [not] too distant to be irrelevant.” Some units also have formal relationships with professional associations, non-governmental organisations, universities, and international agencies.

Working within national networks and, more generally, collaborating rather than competing with other bodies, are a commonly cited strength in how these units are organised. Other cited strengths include a multi-disciplinary approach, an ability to respond quickly to requests, and links with universities. A GSU in a middle-income country cited as a strength: “Focusing in capacity strengthening through apprenticeship of young researchers in health systems and policy research, expose to real policy arena and real life policy analysis and makings”. The cited weaknesses in how the units are organised are also quite diverse: small size, inadequate funding, lack of critical mass of researchers, and difficulties retaining staff, as well as poor communication with stakeholders. As an example of the latter, one respondent wrote: “We have not communicated very well with the public or clinicians about the methods we use and the rationale for decisions made.”

### ***Establishment***

The only theme emerging from among responses to the series of questions about why and how the unit was established is the advice that those establishing a similar organisation attend to the need for secure funding. For example one respondent said: “Be clear about the vision, mission and get the right people well balanced in terms of passion and evidence base - have a secured funding!” Another said: “Try and secure financial independence via core funding as early in the process as possible.” No themes emerged in response to the question about what background documents or resources were helpful in establishing the unit or the question about what other information would have been helpful in establishing the unit.

### ***Methods used in producing a product or delivering a service***

While units tend to describe themselves as being ‘demand-driven’ (with the demand coming directly from government or indirectly from industry in terms of the appearance of a new drug or technology on the market) and less commonly indicate that they work out a consensus about priority topics with stakeholders, they do not cite explicit criteria as the basis for their priority-setting. No themes emerged among the diverse set of strengths and weaknesses cited in reference to the methods used by the units. Examples of strengths include using evidence-based approaches, focusing on cost-effectiveness, credibility, and openness and transparency while examples of weaknesses include not assessing local needs and opportunities (“priorities are sometimes donor-driven and do not result from a systematic analysis of needs and opportunities”), not obtaining clarity in the research question, the time-consuming nature of the methods, few or weak data, and inconsistent involvement of consumers.

### ***Products***

No strengths or weaknesses of the units' outputs were consistently identified by respondents from the units. The cited strengths included high quality, valid methods, scientifically strong, trusted, respected, unbiased (which was equated with a lack of association with drug companies), and having products published in peer reviewed journals. The cited weaknesses included having a small staff or low budget to produce them, being too technical at times, not being transparent or publicly available, taking long to be published, and diffusing only slowly without proactive dissemination and implementation strategies. Several units cited poor dissemination and implementation per se.

### ***Advocates and critics***

The most commonly cited advocates are government health departments with others including academics, stakeholders generally and general practitioners and civil society activists in particular. A mix of critics was identified, including the pharmaceutical industry, some politicians, and some clinicians.

### ***Role of WHO and other international organisations***

As with units that produce CPGs and HTAs, a question gauging views about WHO's and other international organisations' *current* role in developing recommendations and helping policymakers to access and use research evidence did not reap a rich set of responses among GSUs. A question about what role WHO and other international agencies *should* play produced a richer set of responses. The most commonly cited suggestion was that WHO should play a role in helping to adapt global evidence to local contexts or at least in supporting such processes. For example, one respondent suggested that WHO should take "a more proactive role in helping countries adapt existing guidelines to local and regional conditions."

## **PHASE 2: TELEPHONE INTERVIEWS**

The director (or another appropriate person) was interviewed in 25 organisations, including five organisations that produce CPGs, three that produce HTAs, five that produce both CPGs and HTA, and 12 GSUs (Appendix 6). Six organisations were in Western Europe, five in North America, four in Asia, three in Latin America, two each in Africa, Eastern Europe, and the Middle East, and one in Australia. The organisations varied in size from a few people to 50. No organisations declined to participate in the telephone interviews.

### ***Mix of internally produced and externally commissioned work***

The organisations employed a mix of models for producing outputs, with some undertaking some or all of the work internally and others commissioning some or all of the work externally. Seven organisations that produce CPGs, HTAs or both commissioned little or no work (although one was soon to begin), five commissioned some work (up to 25%), and one commissioned most of its work. Six GSUs commissioned little or no work, four commissioned some work, and the other two commissioned about half their work.

### ***Focus of activities***

There was substantial variation in the number and type of activities in which the organisations were involved. All but one of the CPG-producing organisations was involved only

in producing CPGs and the remaining organisation was involved in the education of both physicians and consumers (patients and general public) as well. Most (5/8) of the organisations that produce HTAs or both CPGs and HTAs reported producing systematic reviews as their major activity while three reported undertaking economic analyses and dissemination activities as well. Other activities undertaken by organisations that produce HTAs or both CPGs and HTAs included horizon scanning, preparing CPGs, preparing policy papers, and conducting evaluations (1 each). GSUs reported involvement in a variety of activities, including producing systematic reviews (3 organisations), conducting policy analyses (3), training and capacity building (3), producing CPGs (2), conducting evaluations (2), conducting economic analyses (2), conducting health systems research (2), and undertaking consultations and communication activities (2).

### ***Priority-setting***

All but one of the organisations producing CPGs, HTAs or both used informal methods for setting priorities whereas GSUs were more likely to respond to direct government requests. The exception among organisations producing CPGs, HTAs or both used a scoring system, however, the organisation's director added: "Finally we ask: Is the technology compelling or not compelling? We find most decisions about prioritising are actually intuitive, so we have rolled this in. So, despite the scoring sheet, the most important decision-making about priorities for us is intuitive." Among the organisations producing CPGs, HTAs or both, one organisation reported responding to government requests and four reported consulting with stakeholders. Other criteria that were considered include the frequency and severity of the problem, potential for improvement and cost of achieving the improvement, and avoiding duplication. About half of these organisations reported making decisions internally and about the same proportion reported having a board or advisory group that sets priorities. Turning now to the GSUs, more than half of them (7/12) reported responding to requests for applications, two reported responding to perceived policy needs, and one reported making decisions through consultations involving staff and the Minister of Health. One had a board and one made five-year plans based on an external review.

### ***Methods used in producing a product or delivering a service***

Organisations producing CPGs, HTAs or both tended to conduct or use systematic reviews (12/13) and to have a manual that described the methods they use (11/13). Far fewer convened groups to develop CPGs or HTAs (5/13), took equity considerations into account (1/13) or had established a process for addressing conflicts of interest (1/13). Two organisations described primarily using secondary sources rather than conducting their own systematic reviews. One director said: "We look to secondary sources and based on those we write the final guideline. We don't have staff to do full searches. We think we are still producing good quality evidence-based recommendations, without having to go through 6000 papers." Another reported: "If we haven't got good secondary source material, we go to primary, but that's rare." Only one of the five organisations that convened groups reported using a formal consensus method (the RAND method) and two of the other organisations described using some kind of interactive process with either clinicians or policymakers. The one organisation that takes into account issues of equity said: "The INCLEN method introduces equity. That's one of the aspects of recent guidelines that many of panel members were not able to grasp fully until the end of the process,

but many of them were able to understand at the end of the process.” The one organisation that had a process for addressing conflicts of interest said:

“The conflicts of interest, that’s a modification that we brought. We tried to address conflicts of interest at the very start, during organisation. We are strict with the research committee, who are appraising evidence. We requested them to divest from conflicts of interest, and we actually graded conflicts of interest, especially from the pharmaceutical industry.”

GSUs were less likely to conduct or use systematic reviews (3/12) and to have a manual that described the methods they use (4/12) and more likely to report using non-systematic methods to review the literature (3/12). Several GSUs reported conducting economic analyses and using a variety of methods, including surveys, epidemiological studies, and qualitative studies. One GSU reported working with ethicists and addressing issues of equity. Another GSU described using a highly interactive approach.

“We clarify the research questions, assemble our own team, call them for a meeting, ask senior management what they want answered. Following that we do our literature search. . . . We go back to our senior management and talk again. Then we design our research and bring in necessary competence as needed. We present our methodology to management and once cleared, we proceed with the research. We then do work and present it to different groups, including groups on ‘the ground’. We get as much support as we can from all the groups. . . . We present our findings back to senior management as a draft.”

Using rigorous methods that are systematic and transparent (sometimes shortened to “being evidence based”) was the most commonly cited strength among all organisations. Several organisations that produce CPGs, HTAs or both referred specifically to using “Cochrane methods,” one noted their use of a hierarchy of outcomes, and another noted their use of the GRADE system. The latter director said: “The good thing about GRADE is that it is an honest system which enables you to admit errors or weaknesses. The whole organisation discusses and goes through what is going on every week, and questions things.” The other strengths noted by these types of organisations included using secondary sources (two organisations), “pairing health professionals with our people who have good systematic review skills,” independence from the pharmaceutical industry, and the ability to work with other groups in different countries to avoid duplication of efforts. The weaknesses noted by most of these types of organisations were inadequate resources, more specifically insufficient numbers of skilled staff and time, together with using labour- and time-intensive processes that limit the number and quality of CPGs and HTAs that can be produced and updated.

The GSUs, on the other hand, identified a range of different types of research or evaluation methods as additional strengths, including systematic reviews, measurement of health system performance, economic analyses and surveys. Other strengths noted by GSUs included: having a small organisation that can respond quickly, publishing drafts for public comment, maintaining close links with policymakers, and having independence and financial stability. The weaknesses that were identified by GSUs tended to be limitations of the methods used or how the methods were employed, including: not usu-

ally providing an exhaustive literature search or critical appraisal, “just a systematic review often not being exactly what the audience wants,” use of casual “vote counting” instead of a more rigorous approach to synthesizing research evidence, inaccuracies in long-term forecasting, and limitations in how health system performance is measured. GSUs also identified inadequate human resources and time as weaknesses.

### ***Recommendations or policy decisions related to their products***

There was a great deal of variability both within and across CPG-producing organisations, HTA-producing organisations and GSUs in who makes recommendations or policy decisions related to their products and the processes they use. For example, organisations producing CPGs, HTAs or both in some jurisdictions have full responsibility for making policy decisions whereas in other jurisdictions these decisions are made at the highest levels in the Ministry of Health. Two GSUs based outside of government acknowledged having little understanding of how policy decisions are made. Other GSUs based outside of government complained about the limited role of research evidence in policy decisions. One organisation said: “However, in any political environment, the outcomes are influenced by pressure and political groups, so the quality of the policy decision may be watered down.” Another director said there is “no clear or ongoing structure for policy to be informed by our research.” In contrast, none of the directors based in government spoke of the limited role of research evidence and one said: “Despite evidence, we need to have political understanding, so we need a mixture of both.”

There was also variability in the perceived strengths and weaknesses of the processes that are used to make recommendations or policy decisions. Several directors referred to the explicit use of research evidence as a strength of the process and the time or capacity needed to produce recommendations as a weakness. One person noted: “By the time the unit produces something, the Minister has changed or the issue is no longer on the agenda or there is an election coming up, so there is a discrepancy between the ‘calendars’ of the Minister and the unit.” Another director, describing the lack of capacity said: “The difficult thing in this whole area is that it is early days for this type of reviewing technology. It’s like when we had the first car; it took a long time for the industry to take off. It’s still early days. I can’t hire people who are ready to do this work.”

GSUs more consistently described their close links with policymakers as a strength, particularly those GSUs based in government, whereas organisations producing CPGs, HTAs or both had conflicting viewpoints about such close links. One director from a GSU based in government said: “A strength is that although there are no formal structures, there is a lot of personal contact.” Another said: “Senior management have started to understand evidence-based information.” Two directors from organisations producing CPGs, HTAs or both referred to the split between synthesizing the evidence and making a decision as a strength, whereas another director identified the involvement of stakeholders as a strength, and a fourth said: “One advantage is that we are very closely affiliated with the Ministry of Health. We have shared staff so our recommendations are accepted fairly automatically. We don’t have to go through a courting process. We are part of the process.” Another organisation identified involvement of stakeholders as a weakness as well as a strength: “The problem with groups is that sometimes they have other agendas, particularly with outside experts. . . . Sometimes key experts are very eager to get new procedure out.” Two organisations producing CPGs, HTAs or both noted their lack of influ-



ence as a weakness. One said: “One weakness is that the realm of influence is very small.” The other noted that: “We as an organisation play very little role in terms of influencing policy. We have an interest and mission in doing this, but are not successful at doing this. We are more successful at the clinical level.”

A lack of understanding of evidence-informed decision-making and the need for more education of and communication with policymakers was also noted. “The evidence world is not really joined up yet. It’s really difficult to do EBM [evidence-based medicine] at all because not many people really understand how it works or the impact it can have on organisations. There is a lot of education involved and the policymakers themselves may not have a great understanding of evidence on what it can and can’t do.” Another person linked the need for better understanding of evidence with the ability of vested interests to influence what happens: “Limitation of public funds keeps us from being totally able to communicate the nature of the use of evidence, so without that . . . it’s easy for vested interests to criticize.”

Organisations sometimes mentioned the media as both a strength and a weakness in how recommendations or policy decisions related to their products are made. One director described the attention given to its reports by the mass media as a strength, but the nature of their reporting as a weakness. “We need more professional reporting in the media, to understand the indicators. They can exploit much more what we are reporting. This is a weakness of the media.” Another director added:

“The media is a double-edged sword. We don’t produce press releases, but quite often journalists may come to us for more information. You may produce a piece of research, which may have statistically significant findings. But you know with research you can easily lose control of the implications of your research, because we know that it can be overturned by another piece of research. Media coverage is good, but often media doesn’t understand the subtlety of what we are doing, and the application of the research can be misunderstood and misrepresented.”

### ***Implementing recommendations or policy decisions related to their products***

Most organisations argued that it is the clients who requested a CPG or HTA, the minister of health or more generally the department of health who is responsible for implementing recommendations or policy decisions related to their products. One director said: “The organisation is not allowed to make recommendations, only provide information. Whoever asks for information, it is their responsibility to take it forward and do something with it.” Another director said: “We have very little control of whether recommendations are implemented. It can be quite frustrating. That’s a major drawback. I can’t think of a project where we did implementation. I think this is a limitation. On the other hand, to implement recommendations could require a lot of manpower and we don’t have the authority.” Nearly all GSUs viewed policy implementation as the government’s responsibility, although a couple of directors suggested that individual physicians also have some responsibility. Some organisations noted that responsibility for implementation is frequently spread among several organisations or that it is not clear who is responsible for implementing policy decisions.

All types of organisations tended to focus largely on weaknesses in implementation, with few exceptions. The following statement reflects the tenor of many responses: “Generally the dissemination of policy and link with policy implementation is not as strong as we would like to see.” One reason that was frequently cited for this shortfall was the existence of multiple actors and multiple decision-makers in implementation processes that can be quite decentralized. One director said: “a weakness appears to be that the implementation of policy decisions or recommendations is that it is pretty fractured. This is because the different health authorities or governing bodies take advice from different sources, so there appears to be variation in practice.” Other reasons that were cited for inadequate implementation included the general lack of formal processes for implementation, the specific challenges associated with guideline implementation (e.g., lack of financial incentives for guideline adherence, practical difficulties in engaging health professionals, particularly those in rural areas), and the lack of funds to pay for effective (but expensive) technologies.

Some organisations saw both strengths and weaknesses in particular approaches to implementation. One director said: “A strength is that it starts at the top, with a direction to implement, across hospitals, for example,” but added “a major weakness of this system is that it is asking someone who has no ownership of the guidelines to implement it.” Another director noted that: “Where the Ministry has decided which technologies are going to be incorporated in the national list . . . this is regulated to make sure that this is funded for,” but added: “Sometimes, there is dissension about why certain technologies aren’t added and they are expensive.” A third director identified that: “The main strength is that a decision has been made by the Minister and backed by Cabinet. The actual implementation flows quickly and that’s good.” But the director added: “The weaknesses have to do with the process being watered down by certain stakeholder interests. At this stage, there is still quite an imbalance in the way decisions are handled at national level and at the provincial level.”

### ***Approaches to personal communication with decision-makers***

While informal relationships with policymakers were identified more frequently as important by GSUs (8/12) than by organisations producing CPGs, HTAs or both (4/13), nearly all of the organisations reported using personal communications with decision-makers, particularly policymakers. For organisations producing CPGs, HTAs or both, informal relationships with health professionals (8/13) and academics (5/13) were identified more frequently as important to their organisation than relationships with policymakers, and informal relationships with other HTA organisations (e.g. AHRQ, NICE, and SIGN) (3), the Cochrane Collaboration (2), INAHTA (1), opinion leaders (1), the health services (1), and the public (1) were identified less frequently as important to their organisation. For GSUs, informal relationships with academics (6) and health professionals (3) were identified less frequently as important to their organisation than relationships with policymakers, and informal relationships with advocacy organisations, NGOs, funders, industry, an HTA organisation, and WHO (1 each) were identified even less frequently as important to their organisation. Two organisations reported only having formal organisational relationships and occasionally personal relationships but no informal organisational relationships. While nearly all of the organisations reported using personal communications with decision-makers, a few organisations reported having only ad hoc communication, communication through policy advisors only, or only informal or indi-

rect communication. A few of the organisations considered themselves to be decision-makers, and several others were located within government.

Many of the organisations based within government viewed their close links with policymakers as a strength. “This is a very strong area for us– the fact that we are embedded in government and report directly to the Deputy Minister is what helps. It creates a continuum between the recommendation and the policy decision at the end. We are often called upon by government to explain our work. We don’t seek to be policy decision-makers but we do influence things strongly because of our contacts with government. Sometimes, we are in touch with government on a daily or hourly basis.” Another person working within government responded: “The importance the Minister gives to evaluation is not random. We are part of a government that came to power through a big democratisation process. We were lucky to get rid of a very authoritarian way. [This government places] big demands on accountability. One of the most powerful instruments of accountability is evaluation.”

Organisations based outside of government also viewed their close relationships with policymakers as a strength. “Every month we have a two hour meeting involving all decision-makers. We get them on the phone and make sure we are meeting their requirements. Also, we have some meetings to establish key priorities and so on.” Another responded: “This is a very important component and we are basically constantly exchanging our ideas with respective departments at ministry and national levels, so our informal network is quite important for our research. Policymakers come to us for information and we feel we have access to these people through this contact.” A third director said: “We have to, because of the question setting issues I mentioned. You need to understand what people need.”

### ***Advocates and critics***

Many organisations, particularly those producing CPGs, HTAs or both, indicated that their strongest advocates were health professionals, including front-line clinicians and, especially, those who were involved in the organisations’ activities. One director said: “Our strongest advocates are health care professionals who have been on a guideline group and have had contact with us.” However, physicians, particularly older physicians, specialists and experts, could also be among the most vocal critics. One director said: “The strong critics are maybe the older physicians that do not want to start the process to develop evidence or guidelines. There is more opposition from this kind of physician.” A second director said: “The strongest critics are the elderly people who first of all can’t apply evidence-based medicine, who call themselves experts.” A third director identified a more general source of criticism: “Generally, negative responses come from health professionals who don’t see the guidelines as necessary and think that they get in the way of their clinical freedom.”

The department of health, as well as other regulatory bodies, health insurers, and local health authorities or managers were also frequently identified as strong advocates, both by people working inside government and by those working in organisations based outside of government. Policy-makers could also be critical: “Critics would include the Minister and Director of Social Security, who say we take too much time and that our documents are difficult to translate into simple language.” Another director noted mixed re-

actions from government: members of “the management board of government are cagey because they see the [work we do] as a pressure. On the other hand, the provincial auditors are very pleased because they feel it is an important source of accountability.” Other strong advocates that were identified included satisfied clients, the mass media, speciality societies, and other researchers. The last three were also seen as critics in some jurisdictions or in some circumstances.

The most commonly identified critics were drug companies, particularly when their products were not recommended, and more generally “groups who don’t like our findings; for example, manufacturers or pharmaceuticals.” One director from a organisation producing CPGs said: “We are best friends whenever we recommend a product. We are worst enemies when we say products should not be used. We are independent with no money from the pharmaceutical industry. They were interested in offering us a lot of money.” Another person, commenting on both drug companies and specialists, said: “The strongest critics, often times it’s manufacturers, followed by specialists, well from manufacturers. We receive criticism because they are not happy when assessments are not in their favour. That’s very straightforward. With specialists it’s more subtle. The way it’s perceived, they know more about their area. They resent that anyone would interfere or try to assess.”

Both other stakeholders and competitors were also frequently cited as critics. Stakeholders were generally perceived as critics when a new technology was not recommended: “Some stakeholder groups are wary. They are happy when [we] say ‘yes’ to their new technology proposal based on the work we have done, but not if the answer is ‘no’.” Similarly, another director said: “Naturally there will always be members of the public upset with decisions . . . because there is never enough money to put into everything, so the media and the public will always be critical of those left out.” One person noted some competitors questioning whether the organisation should produce their own guidelines when another organisation was already producing guidelines with 10 times the budget. Another director said: “Our major critics would be some of the organisations who have been around the same time but are more mainstreamed. Cochrane was critical at one stage. . .” Another noted that “the critics can be from academia, strong competitors, they are less consulted, less involved.” A fourth director said “the critics would say we have assumed a monopoly position in the region, which would make it difficult for neighbour countries in the region to get funding for interesting research projects.”

Several organisations also identified as critics those who thought the processes took too long and cost too much and those with different methodological viewpoints. One director commented: “Government . . . is critical because we are not that well resourced, and have to charge for our services, so government is not a strong advocate. Major critics are people who take a prescribed view of what a systematic review of evidence is.” Similarly, another director said: “Our strongest critics tend to fall into three camps. One group says systematic reviews take too long and cost too much compared to other processes, like expert opinion processes. Other groups say we are too restrictive, and then there is a group that feels we are not restrictive enough.” Another director noted: “Our critics would be those people who would like to use our evidence and can’t afford it.”

### ***Examples of successes and failures***

Most of the examples of success among organisations producing CPGs, HTAs or both were occasions where there was a perception that clinicians adhered to the organisation's recommendations or policymakers based their decisions (at least in part) on the work of the organisation. Only one organisation producing CPGs, HTAs or both could not identify an example of success but on the other hand only one organisation cited data from an audit to support the perception that clinicians adhered to the organisation's recommendations. In three of the examples of policymakers acting on the work of an organisation, an intervention was recommended and policymakers' subsequent support for the intervention was perceived as a success. One director who gave several examples said: "I think we have good provision of some expensive devices or drugs that are not widely avail[able] in other countries in region." Another noted a specific example: "We reviewed a new psychiatric drug given to elderly psychiatric patients and supported its supply. It was a good decision because it helped a weak part of the population. It was a drug which has successful results with this group. There is no strong lobby group for these people so it was particularly heartening to see our recommendation get up." In another three of the examples of policymakers acting on the work of a organisation, an intervention was not recommended and policymakers' subsequent lack of support for the intervention was perceived as a success. One director cited a Minister's decision not to start a screening program, and a second cited a Minister's decision not to fund an expensive new technology, despite lobbying. A third director cited the example of a decision not to fund a drug and argued that this decision had saved lives and money:

"It was the whole area of COX-2 inhibitors. About five years ago we attempted to do a systematic review. There was no publicly available evidence. As evidence became available we continued to assess it. We found that their benefits would not justify use. As a result the policymakers made decisions to limit their use. Eventually at least two drugs were taken off the market. Another interesting thing happened. We evaluated utilisation of drugs, so we could compare the impact of that decision. So two things emerged. One, several outside independent groups looked at this. This jurisdiction, because they decided not to have free use, saved money and in terms of real outcomes, actually a big difference between two jurisdictions. [The one] that followed the recommendations; they had fewer deaths and hospitalisations than [the other] that allowed unrestricted use. It has been published."

Two examples of success were drawn from the field of public health: one that addressed smoking cessation, where success was attributed to good timing; the other addressed lowering the legal blood alcohol level for drivers.

The examples of success among GSUs were more diverse and the pathway from research evidence to policy more complex. Several organisations did not identify any examples of success or failure, noting that their role is only to report the research evidence and the decision about whether and how to act on the research evidence is best left to others. The examples of success again tended to represent occasions where policymakers based their decisions (at least in part) on the work of the organisation. One director cited examples of savings and improved accessibility to effective drugs from using generic drugs and supporting local producers. Another director cited savings from the discounts that could be negotiated based on drug class reviews. Other domains where success had been

achieved included evaluations of a national health reform, health care financing policies, implementation of a human resources policy leading to re-categorising health professionals, provision of funds by a donor agency to support local coordination of HIV programs, and a housing policy.

The so-called failures typically involved the perception that clinicians were not adhering to the organisation's recommendations or policymakers were not basing their decisions (at least in part) on the work of the organisation, and the reasons ranged from insufficient awareness-raising among decision-makers to political lobbying by the patient groups, specialists and companies directly affected by the decision. Often the failures involved a technology not being recommended but policymakers deciding to fund it anyway, however, one failure involved a technology being recommended but not being funded by government. Among the four examples of failures that pertained to broader health system policies, two recommendations were complex and a clear explanation was not offered as to why they were not acted upon (even though one would have saved the government money), one recommendation was likely not acted on because it was too broad, and one (involving cuts to the number of hospitals or to the number of beds within hospitals) was likely not acted on due to political opposition. Several other "problems" were noted as well, such as insufficient research evidence, use of an intervention beyond its recommended uses, and inadequate monitoring of adherence to guidelines through audit. One director said: "We did an assessment of helicopter medical emergency services. In 2000 it was equivocal. In some areas more research is needed. That was interesting. It is being used by both opponents and supporters. It was debated in the press for a year and a half. It will be interesting to see what happens. There is not enough data to say." Another director said: "Once you have included something in the list, having it available for a particular condition, may involve it being used for other conditions, so the costs blow out."

### ***Other strengths and weakness***

When asked about any other strengths and weaknesses in how the organisations are organised, directors repeated many of the same strengths that were described previously (e.g., independence, particularly from the pharmaceutical industry, close links to decision-makers, well trained and committed staff, use of rigorous methods, an interdisciplinary, collaborative approach, stakeholder involvement, and international collaboration), as well as many of the same weaknesses (e.g., a lack of well trained staff, insufficient resources, inadequate international collaboration, the amount of time, energy and resources required, and unrealistic expectations of clients). The relatively small size of the organisations was viewed by many organisations either as a strength or as both a strength and a weakness. One director noted: "One of the strengths is being small. Everyone works well with each other. There is a good team spirit; we have very good IT systems. There are 19 people all up in the group." Another noted: "A strength is it is small, a weakness is it is small." Similarly, a third director noted: "The organisation's strength is that it is fairly small and manageable and the staff have different background and skills. Weaknesses include (also) that we are small." The relatively small size of the organisations and the relatively low pay of those working in the organisations were viewed by some organisations as a weakness. One director said: "A weakness is that we don't have enough people to do the work. It's not glamorous, so it's hard to get people." Another noted: "We are low paid." How the organisation is organised was mentioned much less

frequently as a strength or weakness. One director noted that: “One of the weaknesses is the way the organisation is organised. It should be organised into functional teams, rather than on a skills basis. At the moment you’d have all the information officers managed in one team, and not as functional team members supporting the group doing the review. This would be a better way of organising people.”

### ***Advice to others***

The advice offered to those trying to establish similar organisations can be grouped into seven main recommendations.

#### **1. Collaborate with other organisations**

Most directors emphasised collaboration as important both in establishing an organisation and in the ongoing work of a organisation. One director recommended: “Go and see how others do it, don’t reinvent the wheel, lots of people are working on this, the methodology is there if you want it.” Another said: “The most important point is to work in collaboration with others . . . nationally and internationally.” A third director said: “It’s important to work together with organisations in different countries because we can share work and design work, particularly if there are topics of common interest.... you need to be aware that there are a lot of groups doing this sort of work already [internationally]. Find out who they are, and if possible, work with them, rather than duplicate... efforts.”

#### **2. Establish strong links with policymakers and involve stakeholders in the work**

Many directors, particularly those working in GSUs, strongly recommended that organisations “establish links to policymakers.” One suggested: “You need a lot of support from the top level of the ministry. Sometimes your conclusions, recommendations or reports will bother interest groups. If not supported by high officials in the ministry, the reports will end up in drawers of your desk.” The same person went on to describe how they worked with senior policymakers: “We first got together with all of them... We tried to establish good relations with them. You want them to use your information for change. If you from the beginning close communication channels, your information will end up being irrelevant.” A number of directors from across all types of organisations also stressed the importance of involving stakeholders. One suggested: “. . . involve clinicians as much as you can.” Another responded: “In our guideline we invited doctors who we felt were treating the very poor. . . . Disadvantaged populations should be well represented in the panel.” A third said that it is “important to reign in all stakeholders and make them relevant to policy decision-making.”

#### **3. Be independent and manage conflicts of interest among those involved in the work**

While many directors argued for establishing strong links with policymakers and involving stakeholders in the organisation’s work, a number of them highlighted the importance of being independent and managing conflicts of interest. One director working in a GSU suggested you “need an independent organisation, not being commanded.” Another individual, this one working in a organisation producing CPGs, HTAs or both, said: “The most important thing is to keep your independence. We learned it’s very difficult to do that, because a lot of people do have strong conflicts of interest if they are accomplished in their field. It becomes a very difficult thing to maintain.” A director working in the

same type of organisation noted: “Independence seems to be a very important thing and also having very clear conflict of interest guidelines.” Another said: “Address conflicts of interest at the very start of the organisational process, when choosing panellists...” Yet another offered these comments:

“I’ll give an example, quite a big scandal. WHO reviewed and endorsed hypertension guidelines. They lowered threshold, not based on any reliable evidence. At the time it created quite a stir. As people looked in, it became clear that the groups that developed the guidelines had been funded by drug industry. A lot of people were in a conflict of interest. The people in conflict of interest, their interests had been in increasing utilisation of certain drugs, and clear outcome of guidelines, greatly enlarging the pool of patients that would be diagnosed with that condition.”

#### **4. Build capacity among those working in the organisation**

Many directors emphasised the challenge and the importance of recruiting or training multidisciplinary staff. One director noted “Right from start you need trained people. At least two or three.” Another commented: “I think one of the most crucial things is hiring the staff. We have been very lucky with that. Often what we do is employ people on a project basis. We are so dependent on people who work with us, that they are thorough and well trained, and that they share values of transparency.” A third suggested “you have to train everyone.” A couple of directors noted the importance of having a multidisciplinary team and, specifically in LMICs, thinking internationally: “We haven’t hesitated in taking researchers from other backgrounds, so we have an international team... It also means we can build capacity locally.” Several directors, particularly those working in GSUs, emphasised the importance of leadership capacity. One person suggested: “You need good leadership and a lot of networking. Without networking it’s not going to work, because you need good leadership. If senior management is good, it trickles down.” Another recommended that you “got to have someone commit his or her lifetime in this arena. There is a need of many researchers and a good understanding of the whole. You need to understand from the grass roots, the stakeholders’ ideology and power play between different constituencies. All this requires a lifetime work in this arena.... You need to accumulate this understanding and institutionalise this understanding.”

#### **5. Use good methods and be transparent in the work**

Many directors stressed the importance of using good methods and being transparent. One director recommended: “Stick to good methods. That’s the cornerstone. You need to be transparent and evidence based, and everything else really comes from that. Another director, this one from a high-income country, suggested: “Demand excellence in the process of evaluating evidence. Demand excellence and don’t ever do anything to prejudice the results. Make sure your processes are fully transparent.” A director from a middle-income country suggested: “The first thing they need to guarantee is information of good quality. In [low- and middle-income] countries... you can’t aspire to excellent quality, but you can aspire to good information. If people are going to believe you, you need good information.” Another director pointed out the importance of clearly defining the role of experts: “it is important to define the role of health professionals as experts; i.e., we use health professionals on some aspects of questions, but they don’t make the decisions, but help us to make the decision.”



## **6. Start small, have a clear audience and scope, and address important questions**

A number of directors stressed the magnitude of the work involved and hence the importance of starting small, having a clear audience and scope, and addressing important questions. One director noted: "...it's endless work, and sometimes quite overwhelming when you look at what needs to be done. Lots of work for sometimes a small return." Another said: "In general, the work has been well regarded and undertaking it is worth doing, but one shouldn't underestimate the level of work involved." A third suggested: "Start small, because you can easily be swamped with requests. The other important thing is to have a carefully defined audience (client base) and a carefully defined scope." Another suggested: "Start slow, start small but be clear of your own scope and collaborative." A fifth director noted: "... you have to be patient . . . and recognize that it is a time consuming process." And while several directors pointed out the need to address important questions, no consistent advice emerged about how to approach the selection of questions. One director suggested selecting questions that can be answered and to: "make it small enough." Another suggested: "One shouldn't be frightened off by 'insufficient evidence' findings. There is a widespread fear of this. Shining the light where it is currently dark is also worth doing."

## **7. Be attentive to implementation considerations even if implementation is not a remit**

Several directors noted the importance of implementation. One suggested: "Be pragmatic and be affiliated in the process of getting yourself heard, by integrating yourself into the process." A second said: "In general terms, I would want to employ someone with a specific implementation role. A specific dissemination or user-engagement role would be good too." A third person recommended: "You should pay careful attention to getting reviews implemented. Reviews aren't good to anyone if results aren't acted upon." A number of directors who did not comment on implementation had made clear that implementation is not part of their organisations' work, however, some of these directors indicated that implementation considerations still inform their work even if responsibility for implementation lies elsewhere.

### ***Roles for WHO***

Only a small number of directors provided comments about WHO's potential role, however, these comments almost always pertained to the role that WHO is or could be playing in fostering collaborations across organisations. One director noted that "... the work that WHO is doing and getting groups talking to each other" is a step forward. Another noted that: "WHO is very important because it commissions and produces work that is relevant to the European context and promotes a form of networking." A third said: "WHO could provide grants of financial assistance for collaboration between countries. This could improve better health services to larger groups across populations. We exchange a lot of info with Canada and we consult each other. If the WHO could help to coordinate and carry out research on important issues on a global basis this would be very beneficial." A fourth suggested:

"WHO – we all have something to learn from each other. Everyone has slightly different ways of doing things, implementing policies, so sharing information would be great. If we were to use the same methodology in weighing up evidence, there would be better opportunities to share work. We are disappointed that there are not enough

opportunities for collaboration; would like more opportunities for sharing information. Technology is an extensive business, and WHO is uniquely poised to make this technology available to other countries. There must be opportunities for organisations like this one to at least put a portion of our service into helping third world countries. There should be more altruism in this area.”

One director envisioned an additional role for WHO: “There is a need for WHO to play a more active role. We need to market things to policymakers so that our research can be better used. It would be good if WHO could develop guidelines on this.”

### **PHASE 3: CASE DESCRIPTIONS**

The director and one to two staff members, an advocate and at least one critic were interviewed as part of each of the eight site visits, for a total of 51 interviews. A majority of the organisations were GSUs and based in Africa (two directly and one indirectly through a North-South partnership), Asia (two) or Latin America (two). Only one individual declined to participate in the interviews conducted as part of the site visits. Organisations and their advocates and critics highlighted a number of key strengths and weaknesses of the organisations selected for more detailed study, provided advice that could be offered to other organisations trying to support the use of research evidence in developing CPGs, HTAs and health policy, and made suggestions for WHO about how it can facilitate this work. The case descriptions are remarkably varied in the themes that they explore. We highlight here the themes that emerged in two or more cases.

Two organisational strengths were repeatedly cited by individuals participating in the site visits - use of an evidence-based approach and existence of a strong relationship between researchers and policymakers – although each strength brought with it a related challenge (the time-consuming nature of an evidence-based approach and the need to manage the conflicts of interest that can emerge in any close relationship between researchers and policymakers). The examples of using an evidence-based approach are quite diverse: 1) employing an evidence-based approach to drug assessment and prescribing (in Australia and South Africa); 2) adopting an evidence-based CPG-development process that addresses equity as well as effectiveness and efficiency (in the Philippines); 3) relying on systematic reviews of the research literature as a way to protect against vested interests influencing the identification, selection, appraisal and synthesis of research evidence (in Chile); 4) using tried and tested methods that are appropriate to the questions asked (in the United Kingdom); and 5) drawing on health-systems research to inform debate and legislation and incorporating prospective evaluations as part of national health reform (in Mexico). The strong relationship between researchers and policymakers came in the form of both traditional relationships (in Mexico, the Philippines, South Africa, and Thailand) and in the form of some researchers becoming policymakers themselves, which allowed them to bring to the policymaking process their knowledge of research evidence and their contacts within the research community (in Mexico, the Philippines, and Thailand). Site visit participants from east Africa offered several unique perspectives on these relationships: 1) a home-grown model will have a greater likelihood of success; 2) high-level political support is needed for any mechanism that purports to help decision-makers make more informed decisions about health systems; and 3) an

intermediary that can broker relationships between researchers and policymakers constitutes a promising mechanism.

Other strengths were cited less frequently. Only three organisations explicitly identified as a strength their efforts to produce highly relevant products (such as operational research, systematic reviews, CPGs or HTAs), proactively disseminate these products or facilitate access to them. In South Africa their focus on operational research to guide program development was cited as a strength. In Thailand their focus on both operational research and proactively disseminating this research was cited as a strength. And in east Africa their focus on operational research and systematic reviews, as well as their efforts to proactively disseminate this research evidence and facilitate access to it was cited as a strength. Similarly, only three organisations explicitly identified capacity, and specifically long-term investments in human and/or institutional resources, as a strength. The Philippines focused on human resources whereas Mexico and Thailand focused on both human and institutional resources. Two organisations singled out independence or impartiality as a strength: the Philippines in CPG-development processes and Thailand in research generally but also specifically in policy evaluation where they considered independence and impartiality as protections against bias. Two organisations focused on North-South partnerships as a strength, with such partnerships well established in Australia (for example, with Iran and South Africa) and with North-North partnerships established and North-South partnerships only now emerging in the United Kingdom.

Two organisational weaknesses – a lack of resources and the presence of conflicts of interest - were repeatedly cited by individuals participating in the site visits. The lack of both financial and human resources was seen as a weakness in east Africa, South Africa and Thailand, with east African participants in the site visit highlighting that the lack of resources enabled donors an influential role in setting the organisation's direction and with South African participants highlighting the lack of time that can be given by key human resources. The Philippines emphasized a lack of financial resources whereas Chile emphasized a lack of human resources. Conflicts of interest are seen as a major and critical issue in six of the eight countries, however, the context in which these conflicts emerge or how they are expressed varies significantly across countries. Thai participants pointed out that having researchers in very close relationships with policymakers can lead to distortions in their research and that having researchers housed within institutions wholly funded by the Ministry of Health can raise concerns if their independent research contradicts or challenges policymakers. South African participants noted that tension has arisen between researchers and policymakers in their country. Australian participants cited attacks by the pharmaceutical industry and participants from the Philippines pointed out that pharmaceutical company actions and medical equipment ownership can affect clinicians' behaviours. Participants from the United Kingdom indicated that stakeholders can learn how to get around processes and one Mexican participant indicated that politicians can select comparisons that make them or their jurisdiction look good. However, it's important to point out that many of these conflicts of interest are almost always hypothetical and in only one case - the Philippines - are there ongoing challenges in managing it.

Other weaknesses were cited less frequently. Two organisations explicitly identified as a weakness their efforts to proactively disseminate their products (United Kingdom), facili-

tate access to them or both (Mexico). Also, many organisations cited sector-specific weaknesses. For example, participants involved in a site visit of an Australian organisation focused on the pharmaceutical sector identified: 1) the need to look at affordability, not just cost-effectiveness, in developing countries; 2) the need to look at classes of drugs, not each drug individually, to be more efficient; 3) the reality that new drugs have to be compared to old drugs and sometimes old drugs don't work particularly well themselves; and 4) the reality that policymakers sometimes find out later that a drug had advantages or disadvantages that weren't apparent at time of assessment.

Organisations frequently offered two types of advice to those establishing or working in other similar organisations: 1) learn from other organisations (which was supported by participants from Australia, east Africa, Mexico, South Africa, and the United Kingdom); and 2) develop capacity among and retain skilled staff and collaborators (which was supported by participants from Australia, Chile, Mexico, Philippines, and Thailand). While only two organisations (those located in South Africa and Thailand) explicitly recommended that others focus on getting researchers and policymakers to work together, this advice was implicit in the comments of all organisations. Other advice included: 1) involving the full array of stakeholders in any discussions about setting up new organisations or new mechanisms within existing organisations (recommended by participants from east Africa and the United Kingdom); 2) getting the processes or methods right from the beginning (recommended by participants from Mexico and the United Kingdom); obtaining strong political commitment (recommended by participants from Australia although this advice was implicit in the comments made by almost all organisations), and consider equity (recommended by participants from the Philippines although this point was made implicitly by participants from the United Kingdom).

Participating organisations offered a number of suggestions for WHO, however, only two suggestions were offered with any frequency. Participants from five organisations suggested that WHO play a role in mobilizing one or more of government support, financial resources, and the participation of both policymakers and researchers. Participants from east Africa and Thailand spoke to all three of these roles whereas participants from Australia emphasized mobilizing government support and financial resources, participants from Mexico emphasized mobilizing government support (and the support of WHO representatives), and participants from both South Africa and the United Kingdom emphasized mobilizing government support. Participants from three organisations suggested that WHO play a role in creating knowledge-related global public goods. Participants from Mexico emphasized WHO's role in developing and promoting conceptual frameworks, standardized methods, and comparative analyses. Participants from the United Kingdom, on the other hand, recommended that WHO set up the evidence-synthesis component of their country's National Institute for Clinical Excellence for LMICs to use as an input into their own CPG and HTA production processes. Participants from WHO made a somewhat similar point (albeit more implicitly) but they placed the emphasis more on WHO facilitating country collaborations to achieve the same goal. The other advice offered to WHO included: 1) avoid developing global CPGs (the Philippines); 2) lend credibility and support to national CPG-development processes (the Philippines); 3) create awareness about need for free online access to journals in middle-income (as well as low-income) countries (Chile); 4) provide training in use of evidence-based methods

(Chile); 5) issue a general call to develop a more sophisticated understanding of causation and of social inequality (UK).

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## DISCUSSION

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### PHASE 1: SURVEY

#### *Principal findings from the survey*

A high proportion of organisations that produce CPGs, HTAs or both also support government policymaking in other ways, whereas the reverse (GSUs producing CPGs or HTAs) was much less common. More than half of the organisations (and particularly HTA organisations) reported that examples from other countries were helpful in establishing their organisation. The organisations' ages, budgets and production profiles varied dramatically (Table 3). A higher proportion of GSUs than CPG- or HTA-producing organisations involved target users in the selection of topics or the services undertaken. Most organisations had a small number of full-time equivalent (FTE) staff (e.g., five or fewer full-time equivalents for CPG- and HTA-producing organisations). More than half of all organisations always involved an expert in information / library science and more than two thirds of CPG- and HTA-producing organisations always involved an expert in clinical epidemiology. More than four fifths of organisations reported providing panels with or using systematic reviews. GSUs tended to use a wide variety of explicit valuation processes for the research evidence but none with the frequency that organisations producing CPGs, HTAs or both prioritized evidence by its quality. Less than half of all organisations provided a summary of take-home messages as part of their products. Almost two thirds of GSUs involved target users in an implementation group whereas lower proportions of other types of organisations involved target users in implementation through this or another approach. Between one half and two thirds of organisations do not collect data systematically about uptake and roughly the same proportions do not systematically evaluate their usefulness or impact in other ways.

For CPG- and HTA-producing organisations specifically: 1) when they were being established many conducted a focused review of one particular organisation that they then emulated or a broad review of a variety of organisational models; 2) independence is by far the most commonly cited strength in how they are organised and a lack of resources, both financial and human, the most commonly cited weakness; 3) an evidence-based approach is the most commonly cited strength of the methods they use and their methods' time-consuming and labour-intensive nature the most commonly cited weakness; 4) the brand recognition that was perceived to flow from their evidence-based approach and much less commonly from their strict conflict-of-interest guidelines is the main strength of their outputs and the lack of dissemination and implementation strategies for the outputs and the lack of monitoring and evaluation of impact the most commonly cited weaknesses; 5) the individuals, groups and organisations who have worked with them or who have benefited from their outputs are their strongest advocates and the pharmaceutical industry and clinicians who are closely associated with them their strongest critics; and 6) a facilitating role in coordination efforts (in order to avoid duplication) and in local adaptation efforts (in order to enhance local applicability) are their most frequently offered suggestions for WHO and other international agencies.

For GSUs: 1) focusing on the need for secure funding when establishing a GSU was their most commonly offered advice; 2) working within national networks and, more generally, collaborating rather than competing with other bodies, was a commonly cited strength in how these units are organised; 3) government health departments are their strongest advocates; and 4) helping to adapt global evidence to local contexts or at least supporting such processes are their most frequently offered suggestions for WHO. No themes emerged with any consistency among the diverse weaknesses identified in how the units were organised, strengths and weaknesses identified in their methods and outputs, or critics cited.

### ***Strengths and weaknesses of the survey***

The survey has four main strengths: 1) we surveyed the directors of three types of organisations that support evidence-informed policymaking, not just the two types of organisations that are usually studied (i.e., we surveyed GSUs as well as CPG- and HTA-producing organisations); 2) we adapted a widely used questionnaire; 3) we drew on a regionally diverse project reference group to ensure that our draft protocol, study population, and questionnaire were fit for purpose; and 4) we achieved a high response rate (86%). The study has two main weaknesses: 1) despite significant efforts to identify organisations in low- and middle-income countries, just over half (54%) of the organisations we surveyed were drawn from high-income countries; and 2) despite efforts to ask questions in neutral ways, many organisations may have been motivated by a desire to tell us what they thought we wanted to hear (i.e., there may be a social desirability bias in their responses).

### ***What this study adds to previous surveys***

Previous surveys of organisations that support evidence-informed health policies have focused on organisations that develop CPGs [Audet 1990, McGlynn 1990, Grol 1998b, Engelbrecht 1999, Woolf 1999, AGREE 2000, Burgers 2003, Graham 2003] or HTAs [Perry 1997a, Perry 1997b, Sassi 2000, Hailey 2006]. Our survey differs from previous surveys in three important ways. First, we included organisations that produce CPGs or HTAs, and ones that support government policymaking. Second, we included organisations from around the world and sought out GSUs, organisations in LMIC, and CPG and HTA producing organisations that were innovative or successful. We are not aware of any previous surveys that have focused on GSUs or LMIC. One previous survey focused on prominent organisations that develop CPGs [Burgers 2003a]. Thirdly, our survey included a broad range of questions, both closed and open ended, that comprehensively covered the structure, processes and outputs of the spectrum of included organisations.

The survey of 18 CPG producing organisations undertaken by the AGREE Collaboration [Burgers 2003a] is the most recent and comprehensive survey of either CPG or HTA producing organisations. Our findings concur with the conclusions of Burgers and colleagues that “principles of evidence-based medicine dominate current guideline programs”. This is also true for HTA producers and, to a lesser extent, to the broad variety of GSUs that were included in our survey. Our survey also provides further support to their conclusion that “international collaboration should be encouraged to improve guideline methodology and to globalize the collection and analysis of evidence needed for guideline development.” This conclusion appears equally applicable to HTA producers and

GSUs. Beyond expanding the scope of these findings, our survey provides support for further recommendations and provides a richer description of the wide variety of organisational structures, processes and outputs of HTA producers and GSUs, as well as CPG producers around the world.

Hailey and Juzwishin surveyed HTA producers that were members of INAHTA regarding risks for HTA programs and management of those risks [Hailey 2006]. They identified 21 risks under four categories: formulation of HTA questions, preparation of HTA products, dissemination, and contracting. Their findings support the advice that emerged from our study to establish links with policymakers and involve stakeholders, use good methods and be transparent, and be attentive to implementation.

Surveys of CPG and HTA documents [Shaneyfelt 1999, Grilli 2000, Menon 2000, Burgers 2003b, Garcia-Altes 2004, Lehoux 2004] have documented common insufficiencies in CPGs and HTAs and support the advice that emerged from our survey of the importance of using good methods and being transparent as well as advice to collaborate with other organisations and build capacity.

Increasingly governments and others are demanding more rigorous processes to ensure that health decisions are well informed by the best available research evidence. These processes, in contrast with traditional approaches that rely heavily on the opinions of experts, demand systematic and transparent approaches to access, synthesise and interpret research evidence; and to integrate that evidence with other information, values and judgements to formulate recommendations or make decisions. The need for more rigorous processes is underscored by evidence of inconsistencies between the available evidence and expert recommendations [Antman 1992, Oxman 1993], insufficient use of the available evidence [Silagy 2001, Vigna-Taglianti 2006], and other insufficiencies in how guidelines and recommendations are developed [Grol 1998a, Bradbury 1999, Shaneyfelt 1999, Grilli 2000, Horton 2002, Laing 2003, McCarthy 2005, Oxman 2007]. Similar criticisms have been raised and calls have been made for better use of research evidence for health care management and policy making, as well [Lavis 2004, WHO 2004a, WHO 2004b, Lavis 2005, Sheldon 2005, WHA 2005].

## **PHASE 2: TELEPHONE INTERVIEWS**

We conducted the telephone interviews between June and October 2005 with 25 of the organisations included in the survey (Appendix 6).

### ***Principal findings from the telephone interviews***

The organisations employed a mix of models for producing outputs, with some undertaking some or all of the work internally and others commissioning some or all of the work externally. There was also substantial variation in the number and type of activities in which the organisations were involved. All but one of the organisations producing CPGs, HTAs or both used informal methods for setting priorities whereas GSUs were more likely to respond directly to government requests. Organisations producing CPGs, HTAs or both were much more likely than GSUs to conduct or use systematic reviews and to have a manual that described the methods they use. Using rigorous methods that are systematic and transparent (sometimes shortened to “being evidence based”) was the

most commonly cited strength among all organisations whereas organisations producing CPGs, HTAs or both noted inadequate resources coupled with using labour- and time-intensive processes as weaknesses and GSUs noted limitations of the methods used or how the methods were employed as weaknesses.

There was a great deal of variability in who makes recommendations or policy decisions related to the organisations' products, the processes they use, and the perceived strengths and weaknesses in these processes. Several organisations referred to the explicit use of research evidence as a strength of the processes and the time or capacity needed to produce recommendations as a weakness. GSUs more consistently described their close links with policymakers as a strength, particularly those GSUs based in government, whereas organisations producing CPGs, HTAs or both had conflicting viewpoints about such close links. Most organisations argued that it is the clients who requested a CPG or HTA, the minister of health or more generally the department of health who is responsible for implementing recommendations or policy decisions related to their products. With few exceptions, all types of organisations tended to focus largely on weaknesses in implementation, rather than strengths. While informal relationships with policymakers were identified more frequently as important by GSUs than by organisations producing CPGs, HTAs or both, nearly all of the organisations reported using personal communications with decision-makers, particularly policymakers, and many of the organisations viewed their close links with policymakers as a strength. While health professionals (particularly those involved in the organisations' activities) and policymakers were often identified as advocates and drug companies, patient groups and competitors were often identified as critics, particular sub-groups could be supportive or critical depending on their perception of the organisations' general focus (e.g., threatening professional freedom, diminishing the role of expertise, creating funding pressures, and enhancing accountability), its specific approach (e.g., including some forms of research evidence but not others, consulting broadly with affected groups, taking too long or charging a fee to produce a report, and producing reports that are difficult to understand), and its specific recommendations on any given topic (e.g., recommending against providing, covering or reimbursing a technology).

Most of the examples of success among organisations producing CPGs, HTAs or both were occasions where there was a perception that clinicians adhered to the organisation's recommendations or policymakers based their decisions (at least in part) on the work of the organisation. However, the examples of success varied and included efficiently building on work undertaken by other organisations, production of good quality guidelines, providing a basis for political decisions or actions, timeliness, documenting support for current practice, providing support for not using new costly interventions with potential adverse effects or more expensive interventions without documented benefits, increasing delivery of effective interventions, supporting the delivery of effective interventions to disadvantaged or vulnerable populations, linking CPGs to an audits, improving assessments of the quality of care, undertaking assessments of the quality of care, and improved health outcomes.

The examples of success among GSUs were diverse and the pathway from research evidence to policy more complex. Failures typically involved the perception that clinicians were not adhering to the organisation's recommendations or policymakers were not bas-



ing their decisions (at least in part) on the work of the organisation, and the reasons ranged from insufficient awareness-raising among decision-makers to political lobbying by the patient groups, specialists and companies directly affected by the decision. The advice offered to those trying to establish similar organisations can be grouped into seven main recommendations: 1) collaborate with other organisations; 2) establish strong links with policymakers and involve stakeholders in the work; 3) be independent and manage conflicts of interest among those involved in the work; 4) build capacity among those working in the organisation; 5) use good methods and be transparent in the work; 6) start small, have a clear audience and scope, and address important questions; and 7) be attentive to implementation considerations even if implementation is not a remit. Only a small number of directors provided comments about WHO's potential role, however, these comments almost always pertained to the role that WHO is or could be playing in fostering collaborations across organisations.

### ***Strengths and weaknesses of the telephone interviews***

The telephone interviews have four main strengths: 1) we interviewed roughly equal numbers of CPG- and HTA-producing organisations and GSUs; 2) we drew on a regionally diverse project reference group to ensure that our draft protocol and interview guide were fit for purpose; and 3) no organisation declined to participate in the telephone interviews. The telephone interviews have three main weaknesses: 1) despite significant efforts to identify organisations in low- and middle-income countries, just under half (48%) of the organisations we interviewed were drawn from high-income countries; 2) despite efforts to ask questions in neutral ways, many organisations may have been motivated by a desire to tell us what they thought we wanted to hear (i.e., there may be a social desirability bias in their responses); and 3) given the nature of the questions posed and responses given the analysis relied heavily on counting and hence could have missed subtleties in emphasis and inadvertent omissions of select points.

### ***What this study adds to previous interview studies***

We did not find any interview studies comparable to ours, although there have been a large number of case studies of the use of research evidence that have used interviews [Trostle 1999, COHRED 2000, Innvaer 2002, Lavis 2005, Aaserud 2005, Sevene 2005, Tomson 2005, Albert 2007]. These case studies did not focus specifically on CPG, HTA or GSU organisations. Several prior interview studies have focused on specific aspects of HTA producing organisations and not included CPG producing organisations or GSUs [Sassi 2000, McDaid 2003, Lehoux 2004, Hivon 2005, Lehoux 2005].

McDaid undertook a series of face-to-face interviews with prominent individuals associated with HTA and health services research in Canada in 1999 [McDaid 2003]. He found "A key question now being asked by policymakers - implicitly if not explicitly - concerns the value for money from funding HTA organisations. Might funds not be spent better on other activities?" Respondents acknowledged insufficiencies in their ability to document their value for money. These findings and the conclusions he draws support the advice that emerged from this study to collaborate with other organisations and, indirectly, the importance of establishing strong links with policymakers and stakeholders, and to be attentive to implementation considerations even if implementation is not a remit.

Sassi followed up a survey of HTA producing organisations in Europe with interviews [Sassi 2000]. Both the survey and the interviews focused primarily on the impact of EUR-ASSESS, a collaborative project undertaken by European HTA agencies. He found a wide diversity of approaches and the importance of collaboration and shared learning, consistent with the advice to collaborate with other organisations that emerged from our study. Sassi also provides support for the advice to be attentive to implementation considerations, which emerged from this study.

Lehoux and colleagues interviewed directors and staff from six Canadian HTA agencies with a focus on the production [Lehoux 2004] and dissemination of HTAs [Lehoux 2005]. In relationship to the production of HTAs they found tensions between standardising and streamlining production versus diversifying outputs; contextualising results versus sharing work across agencies; addressing a large scope versus one well-delineated question; and doing more versus producing less measurable outputs [Lehoux 2004]. In relationship to dissemination they found that although these HTA agencies had recognised that dissemination activities need to be intensified, why and how particular approaches should be adopted was still under debate [Lehoux 2005]. They also interviewed HTA users and found that significant organisational, scientific, and material limitations hinder the use of scientific evidence and suggested that overcoming such barriers requires a greater commitment from both HTA producers and users [Hivon 2005]. These findings support the advice that emerged from our study to collaborate with other organisations, to use good methods and be transparent, to involve stakeholders, and to be attentive to implementation considerations.

In summary, the findings of our interview study strengthen and enrich the findings of earlier interview studies of HTA producing organisations and suggest that similar advice is relevant to CPG producing organisations and GSUs.

With respect to the suggestion that WHO should foster collaboration across organisations, up to now WHO has not played a leading role among CPG and HTA producing organisations and has, in fact, lagged behind [Oxman 2007]. WHO has however played a leading role in the Evidence-Informed Policy Network (EVIPNet), a WHO initiative to support the establishment of GSUs in LMIC and collaboration across these.

### **PHASE 3: CASE DESCRIPTIONS**

We conducted site visits between September and November 2005 with eight of the organisations included in the survey. A brief description is provided for each of the cases at the end of the report (following the tables) and the video documentaries that were produced are briefly described in Appendix 5.

#### ***Principal findings from the case descriptions***

Two organisational strengths were repeatedly cited by individuals participating in the site visits - use of an evidence-based approach and existence of a strong relationship between researchers and policymakers – although each strength brought with it a related challenge (the time-consuming nature of an evidence-based approach and the need to manage the conflicts of interest that can emerge in any close relationship between researchers and policymakers). Two organisational weaknesses – a lack of resources and

the presence of conflicts of interest - were repeatedly cited by individuals participating in the site visits. Organisations frequently offered two types of advice to those establishing or working in other similar organisations: learn from other organisations and develop capacity among and retain skilled staff and collaborators. While only two organisations explicitly recommended that other organisations focus on getting researchers and policymakers to work together, this advice was implicit in the comments of all organisations. Participating organisations offered a number of suggestions for WHO, however, only two suggestions were offered with any frequency. Participants from five organisations suggested that WHO play a role in mobilizing one or more of government support, financial resources, and the participation of both policymakers and researchers. Participants from three organisations suggested that WHO play a role in creating knowledge-related global public goods.

### ***Strengths and weaknesses of the case descriptions***

The case descriptions have four main strengths: 1) a majority of the organisations were GSUs and based in Africa, Asia or Latin America; 2) we drew on a regionally diverse project reference group to ensure that our case study data-collection protocol was fit for purpose; 3) we drew on 51 interviews, documentary analyses, and previously collected data (from phases 1 and 2) to produce the case descriptions; and 4) only one individual declined to participate in the interviews conducted as part of the site visits. The case descriptions have one main weakness, which they share with the other two phases in the study: despite efforts to ask questions in neutral ways, many organisations may have been motivated by a desire to tell us what they thought we wanted to hear (i.e., there may be a social desirability bias in their responses).

### ***What this study adds to previous case descriptions***

Previous case studies have focused on the use of research evidence for particular decisions rather than on CPG, HTA or GSU organisations [Trostle 1999, COHRED 2000, Innvaer 2002, Lavis 2005, Aaserud 2005, Sevens 2005, Tomson 2005, Albert 2007], on specific technologies [e.g. May 2003, Rotstein 2004, Hastings 2006] or on HTA in specific jurisdictions [e.g. Perleth 2000, Gibis 2003]. Although numerous HTA and CPG organisations have had external evaluations [e.g. Hill 2003, Eskola 2004, Joncheere 2006], these are for the most part reported in unpublished internal documents and they have not been summarised.

The most common finding of systematic reviews of case studies of the use of research evidence to inform health policy decisions [Innvaer 2002, Lavis 2005] is that interactions between researchers and policy-makers increases the prospects for research use by policy-makers. This supports the key finding of our case descriptions and the advice that emerged to establish strong links with policymakers. In contrast, relatively little research appears to have focused on the related challenge of managing conflicts of interest [Boyd 2006].

A second key finding of systematic reviews of case studies of the use of research evidence to inform health policy decisions is that timing and timeliness increases (and poor timing or lack of timeliness decreases) the prospects for research use by policy-makers. This finding supports the other major challenge identified in our case descriptions, the time-consuming nature of an evidence-based approach. Both the importance of deliver-

ing timely evidence to decision makers and the need to do this with limited resources are also reflected in a range of activities being undertaken by CPG and HTA producing organisations both individually and collectively to develop more efficient production processes that are “quick and clean enough” [Oxman 2006].

Apart from EVIPNet [Hamid 2006], which up to now has not obtained substantial financial support, there is little evidence of WHO acting on the most common suggestion from the case descriptions, mobilising support. With respect to the second most common suggestion, creating global public goods, a number of deficiencies in WHO’s use of research evidence have been identified [Oxman 2007], although there are ongoing efforts to address these and improve the quality of WHO’s substantial efforts to provide evidence-based global public goods.

## **PRINCIPAL FINDINGS FROM ALL THREE PHASES COMBINED AND THEIR MEANING FOR OTHER ORGANISATIONS AND FOR WHO**

The seven main recommendations that emerged from the advice offered in the telephone interviews provided a remarkably clear way to organise the principal findings and their implications for other organisations.

### **1. Collaborate with other organisations**

This advice was reinforced by: 1) the (quantitative) survey finding that more than half of the organisations (and particularly HTA organisations) reported that examples from other countries were helpful in establishing their organisation; 2) the (qualitative) survey finding that many organisations producing CPGs or HTAs conducted a focused review of one particular organisation that they then emulated or a broad review of a variety of organisational models; 3) the (qualitative) survey finding that the advice that was most commonly offered by organisations producing CPGs, HTAs or both was to seek support from similar existing organisations or networks, whether through informal interactions, study tours, mentoring relationships, twinning, partnerships or network memberships; 4) the (qualitative) survey finding that working within national networks and, more generally, collaborating rather than competing with other bodies, was a commonly cited strength in how GSUs are organised; and 4) the case descriptions finding that one of the two types of advice offered to other organisations was to learn from other organisations.

### **2. Establish strong links with policymakers and involve stakeholders in the work**

This advice was reinforced by the: 1) the (quantitative) survey finding that a high proportion (88%) of GSUs involved target users in the selection of topics or the services undertaken; 2) the telephone interview finding that, while informal relationships with policymakers were identified more frequently as important by GSUs than by organisations producing CPGs, HTAs or both, nearly all of the organisations reported using personal communications with decision-makers, particularly policymakers; 3) the telephone interview finding that organisations both within and outside government viewed their close links with policymakers as a strength; 4) the case descriptions finding that the existence of a strong relationship between researchers and policymakers was repeatedly cited as one of two organisational strengths (although this strength brought with it a related challenge, namely the need to manage the conflicts of interest that can emerge in any close relationship between researchers and policymakers).

### **3. Be independent and manage conflicts of interest among those involved in the work**

This advice was reinforced by: 1) the (qualitative) survey finding that independence is by far the most commonly cited strength in how organisations producing CPGs and HTAs are organised; and 2) the case descriptions finding that the presence of conflicts of interest was repeatedly cited as one of two organisational weaknesses.

### **4. Build capacity among those working in the organisation**

This advice was reinforced by: 1) the (quantitative) survey finding that most organisations have a small number of full-time equivalent (FTE) staff; 2) and the case descriptions finding that developing capacity among and retaining skilled staff and collaborators was one of their two frequently offered types of advice.

### **5. Use good methods and be transparent in the work**

This advice was reinforced by: 1) the (quantitative) survey finding that between 84% and 100% of organisations reported providing panels with or using systematic reviews; 2) the (qualitative) survey finding that an evidence-based approach is the most commonly cited strength of the methods used by organisations that produce CPGs and HTAs; 3) the telephone interview finding that using rigorous methods that are systematic and transparent (sometimes shortened to “being evidence based”) was the most commonly cited strength among all organisations (although all but one of the organisations producing CPGs, HTAs or both used informal methods for setting priorities; relatively few organisations producing CPGs and HTAs convened groups to develop CPGs or HTAs, took equity considerations into account or had established a process for addressing conflicts of interest; and GSUs were less likely to have a manual that described the methods they use and to conduct or use systematic reviews and more likely to report using non-systematic methods to review the literature); and the case descriptions finding that the use of an evidence-based approach was one of two organisational strengths that were repeatedly cited (although this strength brought with it a related challenge, namely the time-consuming nature of an evidence-based approach).

### **6. Start small, have a clear audience and scope, and address important questions**

This finding was reinforced by: 1) the (qualitative) survey finding that the most commonly cited weakness in how these organisations are organised is a lack of resources, both financial and human; 2) the (qualitative) survey finding that the most commonly cited weakness of the methods used by organisations that produce CPGs and HTAs was their time-consuming and labour-intensive nature; 3) the (qualitative) survey finding that GSUs advised others establishing a similar organisation to attend to the need for secure funding; 4) the telephone interview finding that the weakness noted by most of the CPG- and HTA-producing organisations was inadequate resources, more specifically insufficient numbers of skilled staff and time, together with using labour- and time-intensive processes that limit the number and quality of CPGs and HTAs that can be produced and updated; and 5) the case descriptions finding that a lack of resources was repeatedly cited as one of two organisational weaknesses.

### **7. Be attentive to implementation considerations even if implementation is not a remit**

This advice is reinforced by: 1) the (quantitative) survey finding that less than half of all organisations provided a summary of take-home messages in their products; 2) the (quantitative) survey finding that between one half and two thirds of organisations do not collect data systematically about uptake; 3) the (qualitative) survey finding that the most commonly cited weaknesses of CPG- and HTA-producing organisations' outputs are the lack of dissemination and implementation strategies for the outputs and the lack of monitoring and evaluation of impact; 4) the telephone interview finding that most organisations argued that it is the clients who requested a CPG or HTA, the minister of health or more generally the department of health who is responsible for implementing recommendations or policy decisions; 5) the telephone interview finding that all types of organisations tended to focus largely on weaknesses in implementation when asked about both strengths and weaknesses, with few exceptions; and 6) the telephone interview finding that most of the examples of success among organisations producing CPGs, HTAs or both were occasions where there was a perception that clinicians adhered to the organisation's recommendations or policymakers based their decisions (at least in part) on the work of the organisation.

The four main implications of the findings for WHO and other international organisations can be sorted into four groups.

### **1. Support collaborations among organisations**

This advice is supported by: 1) the (qualitative) survey finding that many CPG- and HTA-producing organisations argued that WHO should play a facilitating role in coordination efforts, primarily to avoid duplication); 2) the telephone interviews finding that when comments about WHO's potential role were offered they almost always pertained to the role that WHO is or could be playing in fostering collaborations across organisations.

### **2. Support local adaptation efforts**

This advice is supported by: 1) the (qualitative) survey finding that some CPG- and HTA-producing organisations argued that WHO should play a facilitating role in local adaptation efforts in order to enhance local applicability; and 2) the (qualitative) survey finding that some GSUs argued that WHO should play a role in helping to adapt global evidence to local contexts or at least in supporting such processes.

### **3. Mobilize support**

This advice is supported by the case descriptions finding that one of only two suggestions that were offered with any frequency was that WHO should play a role in mobilizing one or more of government support, financial resources, and the participation of both policymakers and researchers.

### **4. Create global public goods**

This advice is supported by the case description finding that the second of only two suggestions that were offered with any frequency was that WHO should play a role in creating knowledge-related global public goods, including the development of methods and evidence syntheses.

### ***Strengths and weaknesses of all three phases combined***

The study has six main strengths: 1) we examined the views and experiences of those familiar with three types of organisations that support evidence-informed policymaking, not just the two types of organisations that are usually studied (i.e., we surveyed GSUs as well as CPG- and HTA-producing organisations, we interviewed roughly equal numbers of CPG- and HTA-producing organisations and GSUs, and the majority of case descriptions were GSUs); 2) we achieved both breadth (through a survey) and depth (through telephone interviews with directors and then case descriptions that drew both on interviews with a range of staff, advocates and critics and on documentary analyses) in our examination of their views and experiences; 3) we drew on a regionally diverse project reference group to ensure that our draft protocol, study population, questionnaire, interview schedule, and case study data-collection protocol were fit for purpose; 4) we adapted a widely used questionnaire and achieved a high response rate with our survey (86%); 5) we used explicit sampling criteria to identify particularly successful or innovative groups for more in-depth study through telephone interviews and case descriptions, no organisation declined to participate in the telephone interviews, and only one individual declined to participate in the interviews conducted as part of the site visits; and 6) we employed a variety of independent checks on the credibility of our thematic analyses of the written questionnaire responses and the telephone interview and case study data. The study has two main weaknesses: 1) despite significant efforts to identify organisations in low- and middle-income countries, just over half (54%) of the organisations we surveyed and just under half (48%) of the organisations we interviewed were drawn from high-income countries; and 2) despite efforts to ask questions in neutral ways, many organisations may have been motivated by a desire to tell us what they thought we wanted to hear (i.e., there may be a social desirability bias in their responses). In addition, some issues that were not explored in depth by our study warrant further investigation, such as the ways in which organisations that support the use of research evidence involve and communicate with the general public, the mass media and civil society.

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## **CONCLUSIONS**

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An evidence-based approach is regarded by project participants as the greatest strength in the way these organisations conduct their work, while the time-consuming nature of an evidence-based approach is seen as the greatest weakness. Relationships between researchers and policymakers are seen as highly desirable, but there is little awareness of the nature of potential tensions that can arise and how to manage or resolve them. A lack of resources, both financial and human, poses a challenge in many organisations. Conflicts of interest are seen as a critical issue and freedom from financial links to industry is seen as a highly desirable aim and a great strength if achieved. Multi-disciplinary teams and international networks are seen as highly desirable, and there is a strong perceived need for coordination at an international level to avoid duplication of processes. Little effort is put into dissemination and implementation activities in relationship to the efforts that are focused on gathering, synthesizing and producing evidence-based materials. Negligible efforts are put into communicating evidence to the wider public, via the mass media, and beyond stakeholder constituencies.

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**TABLES - SURVEY RESULTS**

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**TABLE 1: DESCRIPTION OF THE UNITS**

Characteristics	Organisations producing CPGs (N=31)	Organisations producing HTAs (N=19)	Organisations producing CPGs and HTAs (N=45)	Organisations supporting government policymaking (N=57)	All (N=152)
<b>Source</b>					
GIN	13	0	13	3	29
INAHTA	1	17	7	1	26
INCLIN	5	0	5	4	14
Personal contacts	11	2	20	49	82
Other	1	0	0	0	1
<b>Economic classification*</b>					
Low-income	0	0	2	6	8
Lower-middle income	8	1	9	18	36
Upper-middle income	3	0	5	11	19
High income	20	18	27	20	85
<b>Region</b>					
Africa	1	0	1	5	7
Asia	4	1	9	18	32
Australia and New Zealand	1	2	4	2	9
Eastern Europe	0	0	1	0	1
Western Europe	13	12	14	9	49
Latin America and the Caribbean	6	0	6	10	22
Middle East	0	1	0	3	4
North America	6	3	8	8	25
International	0	0	2	2	3

\*International organisations are not included – 2 organisations producing CPGs and HTAs and 2 GSUs.

**TABLE 2: ORGANISATION AND ESTABLISHMENT**

Characteristics	Organisations producing CPGs (N=31)	Organisations producing HTAs (N=19)	Organisations producing CPGs and HTAs (N=45)	Organisations supporting government policy-making (N=57)
<b>Type of product produced</b>				
Reported also providing direct support to policymakers for developing health policy	17 (55%)	16 (85%)	35 (78%)	-
Reported also producing clinical practice guidelines	-	-	-	17 (30%)
Reported also producing HTAs	-	-	-	11 (19%)
<b>Types of services undertaken in response to requests from public policymakers*</b>				
Identify primary research	-	-	-	36 (63%)
Identify systematic reviews of research	-	-	-	31 (54%)
Identify clinical practice guidelines, HTAs or other prescriptive research-based documents	-	-	-	24 (42%)
Undertake short-term research projects	-	-	-	45 (79%)
Undertake systematic reviews of research	-	-	-	38 (67%)
Commission systematic reviews of research	-	-	-	17 (30%)
Either undertake systematic reviews of research or commission systematic reviews of research	-	-	-	41 (72%)
Convene expert meetings to discuss available research	-	-	-	47 (82%)
Other	-	-	-	18 (32%)

\*More than one answer was possible for the question

**TABLE 2: ORGANISATION AND ESTABLISHMENT (continued)**

Characteristics	Organisations producing CPGs (N=31)	Organisations producing HTAs (N=19)	Organisations producing CPGs and HTAs (N=45)	Organisations supporting government policy-making (N=57)
<b>Type of organisation*</b>				
Academic institution	7 (23%)	7 (37%)	11 (24%)	21 (37%)
Disease-specific association	1 (3%)	0 (0%)	1 (2%)	0 (0%)
Professional association	14 (45%)	2 (11%)	4 (9%)	3 (5%)
Government agency	9 (29%)	12 (63%)	22 (49%)	22 (39%)
International agency	0 (0%)	0 (0%)	3 (7%)	7 (12%)
Other	8 (26%)	2 (11%)	7 (16%)	18 (32%)
<b>Source of funding*</b>				
Biomedical or other for-profit company	7 (23%)	1 (5%)	6 (13%)	6 (11%)
Government	17 (55%)	18 (95%)	38 (84%)	45 (79%)
Other	15 (48%)	3 (16%)	20 (44%)	38 (67%)
<b>Examples from other countries helpful in establishing the organisation</b>				
Yes	18 (58%)	14 (74%)	24 (53%)	30 (53%)
No	8 (26%)	0 (0%)	15 (33%)	17 (30%)
Not reported	4 (13%)	4 (21%)	6 (13%)	7 (12%)

\*More than one answer was possible for the question

**Table 3: Age, budget and production profile**

Characteristics	Organisations producing CPGs (N=31)			Organisations producing HTAs (N=19)			Organisations producing CPGs and HTAs (N=45)			Organisations supporting government policymaking (N=57)		
	N	Median	Range	N	Median	Range	N	Median	Range	N	Median	Range
Median years since began production / service	28	9	2 to 27	18	8	3 to 20	44	7	1 to 27	55	10	0 to 94
Median annual budget (in US dollars)	26	368,275	500 to 15,000,000	16	875,000	125,000 to 21,600,000	38	700,000	5,000 to 40,000,000	41	692,000	1,200 to 51,000,000
Median number of CPGs or HTAs produced per year	31	3	0.5 to 500	17	7	2 to 45	42	7	1 to 300	-	-	-
Median time for production of a CPG or HTA (in months)	31	15	0.3 to 33	17	12	4 to 36	41	10	0.3 to 30	-	-	-



**TABLE 4: FOCUS**

Characteristics	Organisations producing CPGs (N=31)	Organisations producing HTAs (N=19)	Organisations producing CPGs and HTAs (N=45)	Organisations supporting government policy-making (N=57)
<b>Domains from which topics are selected*</b>				
Primary healthcare	26 (84%)	18 (95%)	38 (84%)	41 (72%)
Secondary healthcare	25 (81%)	18 (95%)	33 (73%)	29 (51%)
Tertiary healthcare	20 (65%)	18 (95%)	32 (71%)	26 (46%)
Public health (i.e., health is the objective)	14 (45%)	15 (79%)	33 (73%)	50 (88%)
Health public policy	8 (26%)	9 (47%)	21 (47%)	38 (67%)
<b>Domains in which service is provided*</b>				
Characterizing the problem	-	-	-	42 (74%)
Identifying potential solutions to health problems	-	-	-	47 (82%)
Fitting solutions into health systems (i.e., governance, financial and delivery arrangements)	-	-	-	43 (75%)
Bringing about change in health systems	-	-	-	50 (88%)

\*More than one answer was possible for the question

TABLE 4: FOCUS (continued)

Characteristics	Organisations producing CPGs (N=31)	Organisations producing HTAs (N=19)	Organisations producing CPGs and HTAs (N=45)	Organisations supporting government policy-making (N=57)
<b>Target users*</b>				
Patients / public	18 (58%)	13 (68%)	32 (71%)	-
Physicians	31 (100%)	17 (89%)	43 (96%)	-
Other types of health-care providers	24 (77%)	15 (79%)	35 (78%)	-
Healthcare managers	18 (58%)	18 (95%)	36 (80%)	-
Public policymakers	18 (58%)	19 (100%)	37 (82%)	-
Public policymakers in health departments	-	-	-	50 (88%)
Public policymakers in other departments	-	-	-	36 (63%)
Public policymakers in central agencies (e.g., executive branch)	-	-	-	44 (77%)
Stakeholders	-	-	-	45 (79%)
<b>Involvement of target users in selection of topics or services undertaken</b>				
By participation in priority-setting group or working groups	18 (58%)	13 (68%)	28 (62%)	50 (88%)
By survey of views/preferences	14 (45%)	6 (32%)	20 (44%)	35 (61%)
By review of draft list of priority topics or draft reports	15 (48%)	5 (26%)	21 (27%)	43 (75%)
No	6 (19%)	2 (11%)	7 (16%)	0 (0%)
Not reported	1 (3%)	1 (5%)	1 (2%)	3 (5%)

\*More than one answer was possible for the question

**TABLE 5: PEOPLE INVOLVED IN PRODUCING A PRODUCT OR DELIVERING A SERVICE**

Characteristics	Organisations producing CPGs (N=31)	Organisations producing HTAs (N=19)	Organisations producing CPGs and HTAs (N=45)	Organisations supporting government policy-making (N=57)
<b>Average number of members in a CPG or HTA development panel</b>				
1-5 full time equivalents (FTE)	17 (55%)	11 (58%)	23 (51%)	-
6-10 FTE	9 (29%)	5 (26%)	11 (24%)	-
11-15 FTE	2 (6%)	0 (0%)	5 (11%)	-
16-20 FTE	1 (3%)	1 (5%)	1 (2%)	-
> 20 FTE	2 (6%)	1 (5%)	3(7%)	-
Not reported	1 (3%)	1 (5%)	1 (2%)	-
<b>Average number of staff involved in service delivery</b>				
< 0.5 full time equivalents (FTE)	-	-	-	8 (14%)
0.5 – 1.9 FTE	-	-	-	6 (11%)
> 2 FTE	-	-	-	37 (65%)
<b>Types of experts / stakeholders who were always involved*</b>				
Information / library science	19 (61%)	16 (84%)	27 (60%)	29 (51%)
Clinical epidemiology	21 (68%)	14 (74%)	32 (71%)	24 (42%)
Biostatistics	3 (10%)	6 (32%)	17 (38%)	23 (40%)
Health economics	5 (16%)	10 (53%)	17 (38%)	24 (42%)
Other types of social scientists	4 (13%)	4 (21%)	12 (27%)	23 (40%)
Knowledge transfer / communications	10 (32%)	8 (42%)	21 (47%)	24 (42%)
Consumer	9 (29%)	3 (16%)	17 (38%)	15 (26%)
Other	7 (23%)	9 (47%)	13 (29%)	15 (26%)

\*More than one answer was possible for the question

TABLE 5: PEOPLE INVOLVED IN PRODUCING A PRODUCT OR DELIVERING A SERVICE (continued)

Characteristics	Organisations producing CPGs (N=31)	Organisations producing HTAs (N=19)	Organisations producing CPGs and HTAs (N=45)	Organisations supporting government policy-making (N=57)
<b>Types of experts / stakeholders who were involved only if necessary*</b>				
Information / library science	10 (32%)	2 (11%)	13 (29%)	22 (39%)
Clinical epidemiology	8 (26%)	4 (21%)	11 (24%)	22 (39%)
Biostatistics	16 (52%)	12 (63%)	19 (42%)	26 (46%)
Health economics	15 (48%)	9 (47%)	23 (51%)	26 (46%)
Other types of social scientists	14 (45%)	15 (79%)	26 (58%)	24 (42%)
Knowledge transfer / communications	8 (26%)	8 (42%)	9 (20%)	23 (40%)
Consumer	12 (39%)	11 (58%)	11 (24%)	24 (42%)
Other	2 (6%)	4 (21%)	3 (7%)	5 (9%)
<b>Involvement of target users in product development or service delivery</b>				
By participation in development / delivery group	25 (81%)	11 (58%)	33 (73%)	-
By survey of views/preferences	9 (29%)	2 (11%)	18 (40%)	-
By review of draft product or service model	22 (71%)	9 (47%)	32 (71%)	-
No	0 (0%)	3 (16%)	3 (7%)	-
Not reported	0 (0%)	2 (11%)	1 (2%)	-
<b>Involvement of consumers (patients or general public) in product development or service delivery</b>				
By participation in development group	12 (39%)	3 (16%)	16 (36%)	25 (44%)
By survey of views/preferences	9 (29%)	2 (11%)	14 (31%)	31 (54%)
By review of draft guideline (or HTA)	14 (45%)	5 (26%)	23 (51%)	17 (30%)
No	10 (32%)	9 (47%)	13 (29%)	15 (26%)
Not reported	1 (3%)	2 (11%)	1 (2%)	1 (2%)
<b>Criteria used in expert and/or target user selection*</b>				
Geographic balance	21 (68%)	7 (37%)	18 (40%)	-
Gender balance	8 (26%)	2 (11%)	8 (18%)	-
Other	18 (58%)	11 (58%)	25 (56%)	-

\*More than one answer was possible for the question

**TABLE 6: METHODS USED IN PRODUCING A PRODUCT OR DELIVERING A SERVICE**

Characteristics	Organisations producing CPGs (N=31)	Organisations producing HTAs (N=19)	Organisations producing CPGs and HTAs (N=45)	Organisations supporting government policy-making (N=57)
<b>Types of information provided to the panel or employed*</b>				
Systematic reviews	31 (100%)	16 (84%)	42 (93%)	49 (86%)
Economic evaluations	15 (48%)	15 (79%)	24 (53%)	34 (60%)
Decision analyses	13 (42%)	9 (47%)	23 (51%)	29 (51%)
Existing burden of disease/illness	26 (84%)	17 (89%)	34 (76%)	38 (67%)
Existing practice patterns	21 (68%)	14 (74%)	33 (73%)	33 (58%)
Existing guidelines (or HTAs)	30 (97%)	15 (79%)	41 (91%)	38 (67%)
Resource constraints	11 (35%)	10 (53%)	18 (40%)	26 (46%)
Commissioned research	-	-	-	27 (47%)
Other	7 (23%)	5 (26%)	9 (20%)	10 (18%)
<b>Explicit valuation process used*</b>				
Evidence is prioritized by its quality	30 (97%)	17 (89%)	41 (91%)	40 (70%)
Outcomes are prioritized by their importance to those affected	19 (61%)	10 (53%)	28 (52%)	39 (68%)
Groups are prioritized by their importance to achieving equity objectives	8 (26%)	0 (0%)	11 (24%)	27 (47%)

\*More than one answer was possible for the question

TABLE 6: METHODS USED IN PRODUCING A PRODUCT OR DELIVERING A SERVICE (continued)

Characteristics	Organisations producing CPGs (N=31)	Organisations producing HTAs (N=19)	Organisations producing CPGs and HTAs (N=45)	Organisations supporting government policy-making (N=57)
<b>Methods used to formulate recommendations*</b>				
Subjective review	5 (16%)	5 (26%)	12 (27%)	26 (46%)
Informal consensus	10 (32%)	9 (47%)	11 (24%)	28 (49%)
Formal consensus (e.g., nominal group or Delphi techniques)	18 (58%)	3 (16%)	19 (42%)	29 (51%)
Graded according to the quality of the evidence and/or the strength of the recommendation (using an explicit rating scheme)	26 (84%)	12 (63%)	34 (76%)	31 (54%)
<b>Explicit assessments used in formulating recommendations*</b>				
Quality of evidence	29 (94%)	16 (84%)	43 (96%)	41 (72%)
Trade-offs between benefits and harms	20 (65%)	9 (47%)	35 (78%)	35 (61%)
Costs	14 (45%)	12 (63%)	30 (67%)	31 (54%)
Equity	9 (29%)	6 (32%)	21 (47%)	27 (47%)
<b>Review processes used*</b>				
Clinical or policy validation (e.g., pilot testing, trial implementation period)	9 (29%)	3 (16%)	11 (24%)	24 (42%)
Comparison with products or input from other groups	15 (48%)	5 (26%)	27 (60%)	19 (33%)
Internal review	26 (84%)	17 (89%)	38 (84%)	41 (72%)
External review by experts	24 (77%)	16 (84%)	42 (93%)	43 (75%)
External review by target users	18 (58%)	5 (26%)	21 (47%)	23 (40%)

\*More than one answer was possible for the question

**TABLE 7: PRODUCTS AND IMPLEMENTATION**

Characteristics	Organisations producing CPGs (N=31)	Organisations producing HTAs (N=19)	Organisations producing CPGs and HTAs (N=45)	Organisations supporting government policymaking (N=57)
<b>Versions produced*</b>				
Full version with notes/references	31 (100%)	19 (100%)	44 (98%)	46 (81%)
Executive summary	20 (65%)	19 (100%)	32 (71%)	40 (70%)
Summary of take-home messages	14 (45%)	5 (26%)	20 (44%)	25 (44%)
Separate summaries / versions for different target users	10 (32%)	5 (26%)	21 (47%)	24 (42%)
Tools for application (e.g., algorithms, flow charts)	18 (58%)	2 (11%)	26 (58%)	28 (49%)
Produce at least one of the above 4 versions	27 (87%)	19 (100%)	37 (82%)	49 (86%)
<b>Dissemination / implementation strategies used*</b>				
Send versions of products to the media	21 (68%)	10 (53%)	27 (60%)	32 (56%)
Mail or e-mail products to target users	19 (61%)	15 (79%)	33 (73%)	38 (67%)
Produce a CD-ROM and distribute it to target users	6 (19%)	2 (11%)	17 (38%)	20 (35%)
Post to a website accessed by target users	27 (87%)	13 (68%)	32 (71%)	42 (74%)
Submit to a clearing-house	16 (52%)	11 (58%)	17 (38%)	8 (14%)
Other	20 (65%)	9 (47%)	18 (40%)	20 (35%)
<b>Other implementation strategies used*</b>				
Patient-mediated interventions	7 (23%)	2 (11%)	11 (24%)	8 (14%)
Provider-mediated interventions	15 (48%)	6 (32%)	18 (40%)	23 (40%)
Organisational interventions	15 (48%)	10 (53%)	18 (40%)	27 (47%)

\*More than one answer was possible for the question

TABLE 7: PRODUCTS AND IMPLEMENTATION

Characteristics	Organisations producing CPGs (N=31)	Organisations producing HTAs (N=19)	Organisations producing CPGs and HTAs (N=45)	Organisations supporting government policymaking (N=57)
Strategies used to develop the capacity of target users to acquire, assess and use products they produce or services they deliver*				
Organise training workshops for target users	19 (61%)	12 (63%)	31 (69%)	42 (74%)
Participate in training workshops for target users	17 (55%)	8 (42%)	31 (69%)	36 (63%)
Either organise or participate in training workshops for target users	25 (81%)	12 (63%)	34 (76%)	43 (75%)
Develop a resource document for target users	19 (61%)	10 (53%)	26 (58%)	38 (67%)
Other	5 (16%)	6 (32%)	5 (11%)	5 (9%)
Involvement of target users in implementation				
By participation in implementation group	15 (48%)	8 (42%)	26 (58%)	37 (65%)
By survey of views / preferences	9 (29%)	6 (32%)	18 (40%)	28 (49%)
By review of draft implementation strategy	10 (32%)	5 (26%)	14 (31%)	19 (33%)
No	8 (26%)	3 (16%)	5 (11%)	1 (2%)
Not reported	2 (6%)	3 (16%)	9 (20%)	9 (16%)

\*More than one answer was possible for the question



**TABLE 8: EVALUATION AND UPDATE PROCEDURES**

Characteristics	Units producing CPGs (N=31)	Units producing HTAs (N=19)	Units producing CPGs and HTAs (N=45)	Units supporting government policymaking (N=57)
<b>Collect data systematically about uptake</b>				
Yes	11 (35%)	6 (32%)	14 (31%)	20 (35%)
No	20 (65%)	13 (68%)	28 (62%)	32 (56%)
Not reported	0 (0%)	0 (0%)	3 (7%)	4 (7%)
<b>Systematically evaluates usefulness or impact in other ways</b>				
Yes	10 (32%)	9 (47%)	20 (44%)	23 (40%)
No	21 (68%)	9 (47%)	22 (49%)	29 (51%)
Not reported	0 (0%)	1 (5%)	3 (7%)	5 (9%)
<b>Updates products and services</b>				
Updates regularly	16 (52%)	2 (11%)	14 (31%)	21 (37%)
Updates irregularly	14 (45%)	12 (63%)	27 (60%)	28 (49%)
Updates either regularly or irregularly	29 (93%)	13 (68%)	38 (84%)	48 (84%)
Do not update	2 (6%)	5 (26%)	7 (16%)	5 (9%)
Not reported	1 (3%)	1 (5%)	3 (7%)	4 (7%)

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## CASE DESCRIPTIONS

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1. **East Africa** – An initiative to create a multi-national organisation that will act as a bridge between research and policy in the East African Community (comprising Kenya, Tanzania, and Uganda)
2. **Thailand** – A constellation of research organisations that informed the development and evaluated the implementation of Thailand’s nascent universal health insurance program, known popularly as the 30 Baht scheme
3. **Free State, South Africa** – A set of long-term relationships between provincial policy-makers and researchers and the tensions that can arise in these relationships
4. **Australia and South Africa** – An evidence-based drug assessment and pricing scheme in Australia and South Africa
5. **Philippines** – An initiative to address conflicts of interest and inequity in the production of clinical practice guidelines
6. **Chile** – An initiative to use clinical practice guidelines to make the best use of scarce resources
7. **United Kingdom** – An organisation producing guidelines and health technology assessments with a new focus on producing evidence-based public health guidelines to address health inequalities
8. **Mexico** - A comprehensive effort to draw on research evidence to inform the development, implementation and evaluation of the new health insurance scheme

### **CASE DESCRIPTION 1: EAST AFRICA – AN INITIATIVE TO CREATE A MULTI-NATIONAL ORGANISATION THAT WILL ACT AS A BRIDGE BETWEEN RESEARCH AND POLICY IN THE EAST AFRICAN COMMUNITY (COMPRISING KENYA, TANZANIA, AND UGANDA)**

#### ***Interviewees***

- Dr Nelson Sewankambo, Makerere University, Uganda
- Godfrey, Patient, Uganda
- Dr Francis Runumi, Ministry of Health, Uganda
- Dr Emmanuel Kajjuka, Ministry of Health, Uganda
- Robert Mayanje, Provincial health worker, Uganda
- Dr Miriam Were, National Aids Control Council, Kenya
- Dr Davy Koech, Kenya Medical Research Institute, Kenya
- Dr Hassan Mshinda, Ifakara Health Research and Development Centre, Tanzania
- Dr Gabriel Upunda, Ministry of Health, Tanzania
- Dr Leonard Mboera, National Institute for Medical Research, Tanzania
- Dr Stanley Sonoiya, East African Community
- Dr Don de Savigny, Swiss Tropical Institute, Switzerland

The REACH-Policy Initiative will build a bridge between evidence, policy and practice in the East African Community (EAC), with the goal of improving people’s health and health equity

“through more effective use and application of knowledge.”<sup>1</sup> First debated in 2001, the initiative has slowly won the support of many key stakeholders in Kenya, Tanzania, and Uganda. Following consultative workshops with senior officials in all three countries through 2004-2005, it now has the official backing of both the EAC and all national governments. As this report goes to press, REACH is waiting for funding before the organisation can officially hire staff and begin operations.

According to Dr Nelson Sewankambo, one of the driving forces behind the initiative, REACH will be a “clearing-house” for evidence, with a two way flow: working with the research community REACH staff will synthesize evidence for policymakers, and in turn policymakers will use REACH staff to send to the research community important health questions that require answers. For Dr Miriam Were, president of the National Aids Control Council in Kenya and an enthusiastic supporter, REACH will develop an all-important relationship between researchers and policymakers, to enable the people of East Africa to use existing knowledge better, to fight public health challenges like HIV/AIDS. “I know that at least in Africa, if we were able to put to use even a quarter of what we know, the lives of our people would be different.”

Physically REACH will be headquartered in Arusha, the center of the East African Community, but it will have ‘nodes’ in each of the member nations, most likely based out of existing institutions, like the Kenya Medical Research Institute in Nairobi (KEMRI). KEMRI director Dr Davy Koech is also a strong supporter of REACH, but argues that similar research-to-policy work was already underway. “There was a feeling that nothing like that was going on, while at the Kenya Medical Research Institute itself, we have a whole centre of more than 40 scientists.”

In a practical sense, REACH staff will deal with clinical evidence supporting the best therapeutic responses to health crises like tuberculosis, malaria and HIV/AIDS, but they will also synthesize evidence about the best way to deliver therapies, and about the best ways to deliver health programs and organise health systems. Dr Were argues REACH will also offer a way for researchers or policymakers in one nation to know what’s happening in neighboring countries. She cites the example of HIV/AIDS control, an area where Uganda has had tremendous success with educational and other interventions.

Dr Sewankambo cites questions about treatments for malaria, or debate about the value of interrupted antiretroviral therapy (ARV), as fields where REACH staff could quickly source the best quality evidence from systematic reviews to help inform policy decisions. Godfrey, a Ugandan man taking part in a research study testing the effects of interrupted ARV treatment, is also enthusiastic about REACH, and the way it will facilitate the uptake of research evidence, like that collected through the study he is taking part in. “The results of this study will now empower the researchers or the policymakers.... how best the drug can be used.”

Surrounded by a desk over-crowded with tall piles of weighty reports, Dr Gabriel Upunda from the Tanzanian Ministry of Health argues that one of the key functions of REACH will be to “simplify” the evidence for policymakers like himself. (The REACH Initiative was in fact inspired by a project run in Tanzania called the Tanzanian Essential Health Intervention Project.) At the Ministry of Health in Uganda, Dr Francis Runumi says it may ultimately be-

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<sup>1</sup> Upunda G, Omaswa F, Nyikal JW. Regional East African Community Health - Policy Initiative: Prospectus. Nairobi, Kenya, 13 March 2005.

come routine practice for policymakers to consult REACH staff, and even seek a green light from the institution, before making major health policy decisions.

Even before REACH has begun to operate formally, its influence is being felt in other parts of the developing world, because of the meticulous nature of its long-term planning, and the importance of the function it will ultimately serve. At a conference in 2005 in Malaysia, principals from REACH shared their processes with others considering setting up similar bridges between research and policy.

The major weakness identified by interviewees was a lack of funding, with the key players waiting for resources from national governments and/or international agencies. A key challenge identified by some of the principles was to minimize any potential ‘turf wars’ that may erupt in an initiative that comprises three different nations.

## **CASE DESCRIPTION 2: THAILAND – A CONSTELLATION OF RESEARCH ORGANISATIONS THAT INFORMED THE DEVELOPMENT AND EVALUATED THE IMPLEMENTATION OF THAILAND’S NASCENT UNIVERSAL HEALTH INSURANCE PROGRAM, KNOWN POPULARLY AS THE 30 BAHT SCHEME**

### ***Interviewees***

- Dr Pongthep, Rural Doctors Association
- Dr Viroj Tangcharoensathien, International Health Policy Program
- Dr Suwit Wibulpolprasert, Ministry of Health
- Dr Sanguan, National Health Security Office
- Dr Suchai Charoenratanakul, Deputy Prime Minister (formerly Health Minister)
- Dr Siriwat Tiptaradol, Health Systems Research Institute

The introduction of the new “Universal Coverage,” or 30 Baht scheme (named after the size of the co-payment), saw the level of Thailand’s uninsured drop from 30 per cent to almost nothing in the few short years since 2001. Its development an example of evidence informing policy, the scheme is now being implemented and evaluated with help from a constellation of research organisations in Thailand, including the Health Systems Research Institute and the International Health Policy Program.

Describing the “triangle that moves the mountain,” the concept developed by Professor Prawase Wasi,<sup>2</sup> Dr Suwit Wibulpolprasert asserts that those generating knowledge must disseminate it to both political decision-makers and to the wider public in order to move progressive social reforms forward - hence knowledge, society and politics comprise the three points of the powerful triangle.

According to Dr Pongthep from the Rural Doctors Association, one of the key changes with the introduction of the Universal Coverage scheme is that healthcare went for many Thais from being a charity to a right. As an example he cited free home visits for the poor and disabled, which he says are now a right under the new scheme, rather than an act of charity by local professionals or hospital managers.

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<sup>2</sup> P Wasi, Triangle that moves the mountain and health systems reform movement in Thailand. Regional Health Forum. <http://w3.whosea.org/rhf/rh4/6h.htm>

The new scheme is managed by the National Health Security Office (NHSO), a public institution whose board of stakeholder advisers are regularly provided with good quality evidence from Thailand's constellation of research institutions, to inform the board's judgements and recommendations. A regular visitor to the NHSO is Dr Viroj Tangcharoensathien of the International Health Policy Program, a specialist in bridging between research and policy, and a researcher currently engaged in evaluating the impact of the 30 Baht scheme. He says "We are very keen to provide research and evidence to formulate policy and at the same time it is our moral responsibility to evaluate the policy... as the person who did not implement the policy we have impartial status to evaluate."

Dr Suwit Wibulpolprasert from the Ministry of Health explains how another piece of evaluation has demonstrated that the proportion of Thais experiencing "catastrophic illness" (healthcare costs causing severe economic hardship) has been slowly falling in recent years, but dipped dramatically after the introduction of the 30 Baht scheme.<sup>3</sup> Dr Wibulpolprasert argues that this evidence, as well as other research, helped persuade the national government to recently increase funding for the 30 Baht scheme, in order to expand the package of benefits it offers.

Dr Viroj Tangcharoensathien says the factors contributing towards a strong bridge between research and policy in Thailand are consistency, a now well established institutionalization of health systems research, and the high quality and credible research that flows from it. Suwit says "If you want to produce evidence you need to have the capacity, you need the structure, you need the institutional structure and good people. We have been investing a lot on institutions and people."

Criticisms and concerns of those interviewed focused on the management of the 30 Baht scheme, rather than on the well established and internationally respected relationship between research and policy in Thailand. Many challenges are being faced with the implementation of the new scheme including: concerns from professionals and hospitals that reimbursement levels are too low; concerns resulting from a redistribution of resources under the new scheme, whereby hospitals based in traditionally well-served parts of Thailand fear they may now be suffering as funds flow more readily to other traditionally less well-served parts of the country; and the access problems for those without identity cards, and those workers who are highly mobile.

A larger question is that of the political independence of researchers housed within institutions wholly funded by the Ministry of Health, like the Health Systems Research Institute and the International Health Policy Program. Dr Tangcharoensathien joked that if research findings were too harsh, the government would "kick you out". He added that this had not happened yet. "I keep my fingers crossed" he smiled.

### **CASE DESCRIPTION 3: FREE STATE, SOUTH AFRICA – A SET OF LONG-TERM RELATIONSHIPS BETWEEN PROVINCIAL POLICYMAKERS AND RESEARCHERS AND THE TENSIONS THAT CAN ARISE IN THESE RELATIONSHIPS**

#### ***Interviewees***

- Sister Soodi, ARV (antiretroviral therapy) nurse, Phomolong clinic

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<sup>3</sup> Data can be obtained from Dr Suwit Wibulpolprasert, Ministry of Health, Thailand.

- Gladys Moeti, Field worker, University of the Free State
- Dr Ron Chapman, Department of Health, Free State
- Mohohlo Stompie, Phomolong Choir Member, Phomolong township
- Dr Dingie van Rensburg, University of the Free State
- Dr Lara Fairall, University of Cape Town
- Dr Kobus Meyer, University of the Free State
- Three young women researchers, all HIV positive and all taking ARVs (anonymous)

Since the early 1990s, policymakers within the provincial government of the Free State in South Africa have worked closely with a small group of researchers on health and health policy related topics. Currently a number of research teams are engaged in the monitoring and evaluation of roll out of antiretroviral therapies (ARVs), including a team from the University of the Free State and the University of Cape Town.

A small clinic in the black township of Phomolong in the Free State is an ideal location to view the research-policy relationship close up. Nurses at the clinic, including the ARV nurse Sister Soodi, have been trained by researchers from the University of Cape Town, including researcher Lara Fairall, as part of a development and research project for the provincial government.

As part of her duties at the Phomolong clinic, Sister Soodi has created a choir of HIV-positive people, and written and produced a number of songs that have become the choir's repertoire. There are plans for a major tour of the Free State. "We are just not singing for fun," says Sister Soodi during a break from regular rehearsals, "We are just letting people to know that AIDS is real. HIV is real." For University of Cape Town researcher Lara Fairall, the choir is "an amazing tool to fight stigma."

The clinic at Phomolong is also the site of an on-going evaluation of the ARV roll out, which is being undertaken by the University of the Free State. Part of that evaluation involves a survey of patient experiences with the ARV program, which according to field workers conducting the interviews, are generally very positive. Patients like choir member Mohohlo Stompie are typical. She is extremely happy that the drugs are extending her life, but like her friends who are also HIV positive, she would like to see the authorities dramatically speed up the program and expand it to keep up with demand. In the Free State an estimated 350 000 have HIV, 48 000 have AIDS, and only 16 per cent of those AIDS sufferers are receiving ARVs.

Overseeing a whole suite of evaluation projects, including the patient experience survey, the University of the Free State's Professor Dingie van Rensburg has become increasingly concerned that the evidence is exposing major deficiencies in the ARV roll-out. At the time of writing this report, a highly critical paper authored by van Rensburg's team was in press.<sup>4</sup> While acknowledging the failure of leadership and other problems at a *national* level, the paper also cited evidence at a provincial level for deficiencies including: a "lack of leadership ...," a "flawed national-provincial relationship," "insecurity in drug supply," "chronic paralysis in decision-making," and "breakdowns in coordination and communication."

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<sup>4</sup> van Rensburg D et al. The Free State's approach to implementing the comprehensive plan: Principles and features, flaws and failures. Manuscript under review.

Dr Ron Chapman, the senior health department official who has worked with Van Rensburg and others over more than a decade, accepts many of the criticisms but defends his department's record, arguing that while the state may be slow, it is putting in place an important evaluative infrastructure for the long term. He is also concerned that if research findings become too critical, the privileged access to data offered to researchers may simply end. "So it's this balance between access and freedom of speech," says Chapman. "The academics can say things and criticize who they want to obviously [and] in the process [they] might offend a whole lot of people—which then closes doors to the researchers." In order to try to politically manage any fall-out from negative research findings, Chapman has instituted a new system of personally scrutinizing every draft research paper that arises from the department's collaborations with researchers. "Any publication that comes out of our collaboration, I first see that and I scrutinize it for what can go out or not. Now obviously that causes unhappiness among the researchers. But I think at the moment, if you offend, then you might have no access."

Like Dingie van Rensburg, Lara Fairall is concerned about the possibilities of a curtailment of academic freedom, but they both believe the rewards of working closely with policymakers outweigh the risks. Fairall is clear on those rewards: "a feeling that you are doing research that is actually relevant and addressing actual needs as opposed to just driving publications." She argues that setting up randomized trials of their educational interventions is one way of protecting against bias, but that some bias is probably inevitable, as researchers get closely involved in the development of health programs that they regard as valuable.

While tensions have developed in these relationships, both sides are being very upfront about how to manage those tensions, suggesting that the Free State is a good case study for others to learn how to manage these sorts of conflicts.

#### **CASE DESCRIPTION 4: AUSTRALIA AND SOUTH AFRICA – AN EVIDENCE-BASED DRUG ASSESSMENT AND PRICING SCHEME IN AUSTRALIA AND SOUTH AFRICA**

##### ***Interviewees***

- Tony Abbott, Minister for Health, Australia
- Dr David Henry, University of Newcastle, Australia
- Dr Sue Hill, World Health Organisation (formerly University of Newcastle, Australia)
- Dr Anban Pillay and Dr Humphrey Zokufa, Department of Health, South Africa
- Ivan Kotze, Pharmaceutical Society of South Africa, South Africa
- Kuben Pillay, Adcock Ingram Limited
- Dr Shekoufeh Nikfar, Drug Selecting Committee, Iran

Australia's national drug formulary, the Pharmaceutical Benefits Scheme, and its rigorous evidence-based approach to drug assessment and pricing is well recognised internationally,<sup>5</sup> and is now influencing the development of similar approaches elsewhere. To describe it briefly, a government-appointed committee (the Pharmaceutical Benefits Advisory Committee, or PBAC) assesses systematic reviews of the research evidence about

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<sup>5</sup> Fox DM, Oxman AD (eds). *Informing Judgment: Case Studies of Health Policy and Research in Six Countries*. New York: Milbank Memorial Fund, 2001.

the benefits, harms and cost-effectiveness of new drugs. The research evidence is supplied by the manufacturer. The committee compares the new drug to existing therapies already on the formulary, makes assessments about value for money, and then makes recommendations to the federal government as to whether the drug should be listed on the publicly funded national formulary, and at what price. The Pharmaceutical Benefits Scheme is a key pillar of Australia's publicly funded universal health insurance scheme, Medicare, and is strongly supported by all sides of Australian politics.

Dr David Henry, a former long-time member of the PBAC says “[t]he key strength of the program, in subsidizing drugs for the entire population, it selects drugs and prices drugs on the basis of the evidence for how well they work.” Tony Abbott, the current Minister for Health in the Liberal Government says “The PBS is an integral part of our health system. It is a good way of trying to ensure that people do get access to drugs, without allowing the drug companies to get away with gouging of people, and I’m not surprised that therefore the PBS is being looked at by other countries such as Latvia, Iran, and South Africa as potential models for their systems.”

Despite strong criticism of the Australian comparative cost-effectiveness methodology from the pharmaceutical industry, including a number of high-profile legal cases against the individual members of the PBAC, the underlying principles are being slowly exported to many nations, particularly low- and middle-income countries. Key researchers including Dr David Henry and Dr Sue Hill have run a number of workshops on the principles of the PBS, in countries including Iran, Latvia and South Africa.

The World Health Organization's Dr Sue Hill, formerly of the University of Newcastle says, “The thing that people get out of the workshops is they go away with confidence.” Dr Anban Pillay, now a senior official within the Department of Health in South Africa, completed his PhD at the University of Newcastle. He says the Australian workshops have been very helpful in empowering officials in South Africa in their negotiations with industry over listing and price. Dr Pillay says “We’re already seeing a lot of pay-off from them. The Essential Drugs Committee has a lot of people on it now who understand the principles of evidence-based medicine and pharmaceutical companies are finding it more difficult to try to push a particular drug to be on the list without providing the necessary evidence.” Post apartheid, the national government has embarked on a multi-phased reform of drug assessment and pricing, primarily designed to make drugs in South Africa's private market more affordable.

As in South Africa, officials in Iran have strongly positive comments on the value of the Australian workshops conducted there. Dr Shekoufeh Nikfar from the Iran Drug Selecting Committee says of the workshops: “They made some idea in our brain that we have to change our system to become an evidence-based system—based on systematic reviews. It was very helpful.”

In South Africa there was strong initial opposition from the pharmaceutical industry to some elements of the reforms that were inspired in part by the principles of the Australian system. That opposition resulted in major legal action. After the industry's legal action ended and its attitude to the reform process became more positive, the nation's retail pharmacists mounted a major case against the national government, over concerns



that fees detailed in draft regulations were inadequate. As Ivan Kotze from the Pharmaceutical Society of South Africa explains, the pharmacists took aggressive action to suspend both the specific regulations and the whole direction of reforms. “To make sure that the fee was not introduced we approached those regulations with a shotgun approach and said ‘stop the regulations.’ It was very difficult to go to court and say the quantum of the fee is not adequate. It’s difficult to point that out and that’s why we went through this whole process of attacking the regulations...but the intention was to stop the dispensing fee.” In the face of on-going action, the national government is moving ahead with plans to ultimately introduce the so called ‘fourth hurdle’ of cost-effectiveness into routine drug regulation. Senior departmental official Humphrey Zokufa said “[w]hen we are considering new drugs for registration, we’ll look at the safety we’ll look at the efficacy, we’ll look at the quality. But we also have to apply our minds to the fourth hurdle which is... is this drug - the way it’s priced - value for money?”

While the loudest critics of the Australian evidence-based approach to drug assessment and pricing has been the pharmaceutical industry, no one from the industry’s representative body in Australia, Medicines Australia, would agree to be interviewed for this report. However, one long-time industry figure commented in a background conversation that industry’s attitude towards the Australian system was changing: initially regarding it as a threat to profits, but now increasingly coming to see it as something of an international model, and hence a place to learn about how to effectively operate in an evidence-based environment.

One of the strongest criticisms of the Australian current approach comes ironically from one of its architects, Dr David Henry, who says a key weakness is that the system assesses drugs individually, in response to requests from individual manufacturers, making it too ‘industry friendly.’ Rather it may be better to examine the cost-effectiveness of whole classes of drugs, or whole health programs, rather than laboriously examine the cost-effectiveness of every new pharmaceutical product. He argues that chiefly as a result of this weakness the PBS has limited applicability as a template for low- and middle-income countries, but that its evidence-based principles are of great value.

## **CASE DESCRIPTION 5: PHILIPPINES – AN INITIATIVE TO ADDRESS CONFLICTS OF INTEREST AND INEQUITY IN THE PRODUCTION OF CLINICAL PRACTICE GUIDELINES**

### ***Interviewees***

- Dr Antonio (Tony) Dans and Dr Leonila (Inday) Dans, University of the Philippines
- Dr Eugene Reyes, a physician working with the Philippines Heart Association on a lipid guideline
- Dr Eduardo Banzon, Philippines Health Insurance Corporation (PhilHealth)
- Dr Mario Villaverde, Assistant Secretary of Health
- Dr Tomas Realize, AstraZeneca Pharmaceuticals

Against the backdrop of a great level of pharmaceutical industry promotional activity, and a situation of multiple ties between companies and individual health professionals, the Philippines Heart Association (PHA) recently produced *The 2004 Clinical Practice*

*Guidelines for the Management of Dyslipidemia in the Philippines.*<sup>6</sup> In order to undertake the guideline, the PHA sought the support of the International Network of Clinical Epidemiologists (INCLEN) and that organisation's methodology was employed. Importantly the method called for the guideline developers to address the problem of inequality in the Philippines and the conflicts of interests of guideline developers.

Long time INCLEN member, Dr Tony Dans argues the problem of the conflicts of interest for guideline developers is a particularly important one in the Philippines because so much of the promotional activity and so many of the financial ties between industry and the profession – e.g., paid consultancies, advisory board memberships, and financial favours – are uncontrolled. He says that as a result that in developing countries “the influence of pharmaceutical companies on clinical [practice] is far greater than what you see in developed countries.”

Inspired by INCLEN's method and approach, the Technical Research Committee of the PHA decided not to seek any pharmaceutical industry sponsorship for the guideline development process, and to then rigorously examine their own ties with industry and those of potential panel members. Committee and panel members were invited to disclose ties or divest them, particularly if they were above a pre-determined threshold. Ironically the chair of the Technical Research Committee, Dr Eugene Reyes discovered through this process that he had the most conflicts of interest of all his colleagues. “I had the highest conflict of interest after we had reviewed everything.”

Deciding to stay with the guideline development process, Dr Reyes slowly undid his financial links with drug companies, one by one, though he still accepts chauffeur driven trips through Manila from drug representatives and invitations to lavish dinner and entertainment events funded by manufacturers. At one event in September 2005, AstraZeneca funded cocktails, wine, beer and dinner for 600 doctors, to ‘celebrate’ the second anniversary of the launch of AstraZeneca's drug Crestor. The medical director of AstraZeneca in the Philippines, Dr Tomas Realize, argued that the event was not wining and dining, but rather scientific education - because some data were made available both after dinner and during pre-dinner cocktails. “I think the wining and dining is a thing of the past”, Dr Realize said, during an interview conducted with him while he was standing in the middle of a large function room surrounded by 600 doctors eating and drinking at the expense of his company.

Despite their willingness to address the problem of conflicts of interest, both the Technical Research Committee of the Philippines Heart Association and the final Panel that developed the guidelines were ultimately riddled with conflicts of interest - all disclosed in the final version of the guideline. The ties included: membership in speakers' bureaux; undertaking company sponsored research; ownership of hospital stock; ownership of medical/laboratory equipment; and accepting travel, convention, sports or leisure sponsorship.

While he had hoped that more of the guideline developers would divest of all financial ties with industry, Dr Tony Dans welcomed the process of rigorously and transparently

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<sup>6</sup> Available from the Philippines Heart Association

addressing conflicts of interest, and regarded it as an important step in the right direction, particularly in a developing world setting. He also welcomes the fact that the guideline developers seriously considered inequalities as part of the process - applying the 'equity lens' in their framing of questions, search of literature and development of recommendations.<sup>7</sup>

Drawing on INCLEN's "Knowledge Management Plus" approach, the guideline developers explicitly considered how any recommendations would affect the Philippines' large disadvantaged population, who cannot afford laboratory tests or drugs. Conceding that these guidelines may not realistically reduce health or economic inequalities in the Philippines, Dr Dans believes that the guidelines should at least not exacerbate them. "Making guidelines like this where you consider inequities at least avoids aggravating the inequities that already exist in society."

The equity-based and evidence-based approach of INCLEN is influencing different sectors of the Philippines health system, and Dr Dans recently won a national service award for his work promoting evidence-based medicine, awarded in 2005 by the President of the Philippines. According to Dr Inday Dans, INCLEN has helped train over 800 clinical epidemiologists who are applying the principles of the evidence-based approach in their work. One of those is Dr Eduardo Banzon, a senior official with the Philippines Health Insurance Corporation, which he says is slowly introducing an evidence-based approach into its decision-making about resource allocation. Dr Banzon hopes that PhilHealth can ultimately use evidence as a protection to defend its decisions against the many criticisms and complaints from manufacturers or patient groups, for example, who may have a narrow focus on a particular technology or medicine.

#### **CASE DESCRIPTION 6: CHILE – AN INITIATIVE TO USE CLINICAL PRACTICE GUIDELINES TO MAKE THE BEST USE OF SCARCE RESOURCES**

##### ***Interviewees***

- Dr Rodrigo Salinas, Dr Gloria Ramirez, Dr Fernando Munoz, Dr Fernando Otaiza O’Ryan and Dr Dolores Toha Torm, Ministry of Health
- Dr Pedro Garcia, Health Minister
- Dr Jorge Jimenez de la Jara, former Health Minister
- Dr David Vilena Pedrero and colleagues, Medical College of Chile
- Dr Jacques Girard, Pan American Health Organisation

As part of a broader health sector reform, the Chilean government is progressively introducing 56 new clinical practice guidelines, between 2005 and 2007. The government has prioritised 56 health problems/conditions, and as part of the reforms, it will guarantee Chileans certain interventions for those 56 conditions, within certain specified time frames. With the backing of the (now former) president Ricardo Lagos, the guideline development process has been explicitly evidence-based.

One example is the new stroke guideline, to be launched in 2006. Among other commitments, the guideline will guarantee Chilean's access to a CT scan, within three days of suffering a stroke. As the practising neurologist and stroke guideline developer Dr Rod-

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<sup>7</sup> INCLEN, Addressing Inequalities in Clinical Practice Guidelines, Draft 23/06/05

Dr Rodrigo Salinas explains, the CT scan is an important way to determine what kind of stroke a person has suffered, in order to offer them optimal treatment. In order to meet these guarantees, Chile will need more technology like CT scanners. In November 2005, a new CT scanner was unveiled at Salvador Hospital, by the Health Minister Dr Pedro Garcia, a strong supporter of using good evidence to inform policy. "When a government like ours is doing public policy you have to make sure that what you are doing is the best way it can be done." In an interview conducted soon after he launched the new CT scanner, the Minister said: "You can spend all your money on [just a] few people, [but] if you know more about an evidence based [approach] maybe you will be able to treat more people, and you will obtain better results at the end."

One of the biggest criticisms of the reforms is the alleged unfairness of the rationing approach, where just 56 conditions have been prioritised, which automatically excludes other conditions. While the vast majority of the burden of disease will be covered by the 56 problems, some people with rare diseases will not have their conditions prioritised. This means that theoretically they can access treatments and care, but they are not prioritised and there is no guarantee they will receive needed treatments within given time frames. The loudest criticism has come from the Medical College of Chile, where members say the "56 guideline reform" is unfair and unworkable.

Defenders of the reforms, including Dr Rodrigo Salinas, who is also a part-time official with the Ministry of Health, say that all health systems ration care -- for example by wait-lists, or ability to pay -- but that Chile has attempted to *explicitly* ration care, in an evidence-based way. According to Dr Salinas, the biggest challenges for Chile are a lack of staff qualified in evidence-based approach and systematic review methodologies and a lack of resources to access research. For example accessing the full text of medical journal articles, which may be needed for a systematic review for example, is beyond the means of the Chilean officials.

A strong supporter of an evidence-based approach, Dr Salinas also argues that it has a 'dark side'. "The evidence based approach has... a dark side, and this dark side is that the evidence comes heavily from interested parties and these interested parties are mainly drug companies." He points out that much of the best evidence comes from the developed world, and that evidence may not always be appropriate in a developing world setting, using as an example the health problems caused by the brain parasite, 'Neurocysticercosis', a disease affecting Chileans, where there is little evidence to support any effective interventions. A rare disease without any effective interventions, 'Neurocysticercosis' has not been prioritised as one of the 56 conditions, so there is no new guideline being developed for it.

In order to try and generate relevant research evidence, for a Chilean setting, and with a public health focus, Chile has recently created a new special research fund, which Salinas hopes will start to correct the imbalance in evidence.

While the election of the new Bachelet government will consolidate political stability in Chile, the future of the reforms, and the controversial 56 guidelines, is uncertain.

## **CASE DESCRIPTION 7: UNITED KINGDOM – AN ORGANISATION PRODUCING GUIDELINES AND HEALTH TECHNOLOGY ASSESSMENTS WITH A**

## NEW FOCUS ON PRODUCING EVIDENCE-BASED PUBLIC HEALTH GUIDELINES TO ADDRESS HEALTH INEQUALITIES

### *Interviewees*

- Dr Mike Kelley, Dr Peter Littlejohns, Dr Andrew Dillon, Andrea Sutcliffe, and Dr Gillian Leng, National Institute for Health and Clinical Excellence (NICE)
- Michael Davidson, citizen's representative on NICE committee
- Dr Richard Smith, former BMJ editor
- Henry, Richard's dog

In 2005 the United Kingdom's internationally respected National Institute for Clinical Excellence (NICE) augmented its mission to include public health objectives and became the National Institute for Health and Clinical Excellence. As well as producing clinical practice guidelines and health technology assessments, the new body will now produce public health guidelines as well. The first such guideline is due in 2006 and will target physical inactivity. "In Britain we need to get the whole population moving more and we need to shift the whole curve towards more activity" says Dr Mike Kelly, who is running the public health area within the newly expanded NICE.

NICE staff believe that the evidence-based manner in which they are integrating clinical and public health approaches is ground-breaking. "This is first time anywhere in the world that a body has been given responsibility for both clinical and public health work and developing guidance in both areas in an integrated fashion," says Mike Kelly. "It's a real opportunity to bring together and preventive medicine and clinical practice so we can make more than just the sum of the parts and that's what we intend to do," says Andrew Dillon, the chief executive officer of NICE.

Like the INCLEN approach in the Philippines, NICE is also trying to tackle inequalities through its guideline processes, against a backdrop of widening inequality in Britain. As part of that approach the organisation is first trying to get a more rigorous and comprehensive idea of the nature of the many social determinants of health and how they interact to produce health outcomes. Mike Kelly says "we need a much better understanding of the anatomy of the body social than we currently have." It is likely that many nations will benefit from the sophisticated approach to social determinants being undertaken in Britain by Kelly and his colleagues, as NICE is helping provide infrastructure to the new WHO Commission on the Social Determinants of Health.

One of the key strengths of the NICE approach to producing guidelines and health technology assessments is its involvement of stakeholders, including citizen/patient representatives in its decision-making processes. Michael Davidson, a citizen's representative on a NICE committee assessing new procedures and technologies, says his views are widely sought and respected by his peers on the committee. "I have seen the relationship[s] that I have with the colleagues round the table grow, they now see me as a contributor not as an ornament. They listen to what we have to say as lay people." Davidson's views are reinforced by Dr Peter Littlejohns, a senior official at NICE. "The fact that we can have patients, the public, politicians, the industry professionals all debating in a common forum with an explicit evidence base that they can look at and criticise is a way forward."

A strong supporter of NICE, Littlejohns is also candid about valid criticism of the way the high-profile organisation has worked. Echoing criticisms of former *BMJ* editor Dr Richard Smith, Littlejohns agrees that one of the weaknesses of its approach has been too much emphasis on assessing new technologies, at the expense of analysing the benefits, harms and cost-effectiveness of many existing technologies. Part of the problem, according to Littlejohns, is that NICE is directed by the national government as to which technologies to assess.

A long time observer of NICE,<sup>8</sup> Dr Richard Smith argues the organisation should be more autonomous, bolder and more transparent. While he strongly supports the evidence-based approach to making decisions about resource allocation, he believes NICE should be more explicit about the fact that it is helping Britain ration its health resources. In terms of NICE tackling inequalities through its public health guidelines, while Smith welcomes the initiatives he asserts the great limitations in the approach. “The brutal truth is that the healthcare system can only do a very small amount in reducing inequalities in health so if you’ve got economic forces where the rich are getting richer and the poor are getting poorer, and you’ve got rather deep and profound deprivation, its very difficult for the health care system to do much and even public health measures unfortunately [have] only a very limited impact.” When asked his views on evidence-informed health policy, Smiths’ dog Henry declined to comment, and simply wagged his tail.

Like many of the organisations interviewed for this report, NICE was open about the fact that a disproportionate amount of energy is invested producing clinical practice guidelines and health technology assessments, and not enough energy is expended disseminating and implementing them. This function has recently been upgraded at NICE under the direction of Dr Gillian Leng. “In general the focus tends to be on developing the guidance, reviewing the evidence, and doing that step and people do tend to forget that implementation is crucial to make a difference.”

With a budget of more than 20 million GBP, few nations can afford to match the funds the NICE is investing in evidence to inform policy and practice. In order to share the fruits of this investment NICE makes all of its products and processes available free on its website, and is engaged directly with a number of low and middle income nations in helping them develop similar structures.

## **CASE DESCRIPTION 8: MEXICO - A COMPREHENSIVE EFFORT TO DRAW ON RESEARCH EVIDENCE TO INFORM THE DEVELOPMENT, IMPLEMENTATION AND EVALUATION OF THE NEW HEALTH INSURANCE SCHEME**

### ***Interviewees***

- Dr Octavio Gomez Dantes, Ministry of Health
- Dr Julio Frenk, Secretary of Health
- Dr Asa Cristina, Secretary of Health, Federal District of Mexico City
- Dr Mauricio Hernandez and Dr Miguel Gonzales Block, National Institute of Public Health
- Dr Michael Reich, Harvard University, United States

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<sup>8</sup> Smith R, Editors Choice: The triumph of NICE, *BMJ* 2004;329; Smith R, NICE: a panacea for the NHS? *BMJ* 1999; 318:823-824; Smith R The failings of NICE, *BMJ* 2000; 321:1363-1364.

### ***Additional support***

- Dr Felicia Knaul, Ministry of Public Education, Mexico City, Mexico<sup>9</sup>

Over seven years Mexico's national government is rolling out a new system of insurance called the Seguro Popular, or Popular Health Insurance scheme, to extend coverage to the roughly 50 million Mexicans currently not covered by existing programs. The scheme is being progressively introduced across Mexico, starting with the poorest communities first, and offering a defined package of health services. For Mexico's Secretary of Health, Dr Julio Frenk, an internationally recognised expert in the evidence-to-policy bridge, this scheme is a text book case. "I believe this is almost a text book case of how evidence really first of all changed public perceptions, then informed the debate, and then got translated into legislation."

One of the key pieces of initial evidence that sparked widespread debate about the need for reform was the finding that Mexico's old health system, contrary to popular belief, was funded largely regressively through private out-of-pocket contributions. Having informed the debate and the development of the scheme, evidence is now playing a role in evaluation. Taking advantage of the timetable of the progressive roll out, the government has set up a controlled trial comparing the outcomes for those communities receiving the scheme, and those still waiting for it. "I think this is the kind of study that epidemiologists and people in evaluation dream about. I think this could happen because we are in the middle of a political transition that allows this to happen because it's important for democracy."

A long time colleague of Dr Frenk, and a researcher himself, Dr Octavio Gomez Dantes runs the evaluation unit within the Ministry of Health, where they produce an annual report measuring the performance of all 32 Mexican states and districts. The report is launched by the President, has received much media attention, and is taken extremely seriously by provincial governments. "For the first time we compared states...and that's a very powerful tool for stewardship because the federal Ministry can use comparative assessment to stimulate better performance and engage the states in a process of shared learning."

Apart from the well respected Mexican Foundation for Health, one of the most significant providers of evidence in Mexico is the National Institute of Public Health, where Julio Frenk was the founding director, and which along with Harvard University is helping evaluate the Seguro Popular introduced under Frenk's stewardship of the nation's health system. The Institute's current director, Dr Mauricio Hernandez, is a strong supporter of the role of evidence in policy, but he is critical of the fact that the relationship is not better developed in Mexico. "There is not a clear system in terms of how institutes or universities or other research centres can translate the evidence that they have into policy. There is not an agency; there is not a clear mechanism. It depends on the director of the research institute, or the researcher himself who takes the role of an activist."

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<sup>9</sup> Knaul, F, The role of evidence on financial protection in the Mexican health reform of 2003, draft from author.

Another Institute official, Dr Miguel Gonzales Block backs up the comment, explaining that the current Secretary, Julio Frenk, attends weekly meetings with Institute staff, directly facilitating the evidence-to-policy relationship. Despite the close relationship, and the fact that the Ministry funds the Institute, both sides claim strongly that the researchers can maintain their independence from the political process.

One of the highest profile critics of the health policies of Dr Julio Frenk and of the Seguro Popular is Dr Asa Cristina Laurell, the Secretary of Health for the federal district of Mexico City and another long time health researcher. She is critical of the reform because it requires people to pay out-of-pocket costs and because the package offered is not comprehensive. Dr Frenk concedes the package offered by the Popular Health Insurance scheme is limited, but argues it is broad, and that because it is explicit it allows Mexicans to know their entitlements and therefore “they can be demanding of those rights.”

Dr Laurell is also suspicious of emphasis being placed by the national government on *evidence*, when in her view *values* have so much to do with the development of health systems. “I am convinced that you need to use evidence but I also know that you have to choose very well the evidence that you are going to use because otherwise you can prove practically anything if you use your evidence in a particular way.”

Protection against the misuse of evidence flows from the rigour and credibility of those who produce it, at research houses like the Mexican Foundation for Health and the National Institute of Public Health. Moreover, in Mexico, currently, people like Octavio Gomez Dantese see the evidence that flows from evaluative research, such as the controlled study of the Seguro Popular, as being central to the nation’s reinvigorated democracy, ultimately offering accountability to those paying for the health system through their taxes.



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# Appendices

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## APPENDIX 1: PROJECT REFERENCE GROUP

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- Atle Fretheim, Norwegian Knowledge Centre for the Health Services, Norway
- Don de Savigny, Swiss Tropic Institute, Switzerland
- Finn Borlum Kristensen, Danish Centre for Evaluation and Health Technology Assessment, Denmark
- Francisco Becerra Posada, National Institutes of Health, Mexico
- Jean Slutsky, Agency for Healthcare Research and Quality, United States
- Jimmy Volminck, Stellenbosch University, South Africa
- Judith Whitworth, Advisory Committee on Health Research, World Health Organisation
- Marjukka Makela, Finnish Office for Health Care Technology Assessment, Finland
- Mary Ann Lansang, University of the Philippines, Philippines
- Mike Kelly, National Institute for Health and Clinical Excellence, United Kingdom
- Peter Tugwell, University of Ottawa, Canada
- Rodrigo Salinas, Ministry of Health, Chile
- Sue Hill, Medicines Policy and Standards, World Health Organisation, Switzerland (formerly University of Newcastle, Australia)
- Suwit Wibulpolprasert, Ministry of Health, Thailand
- Suzanne Fletcher, Harvard University and University of North Carolina at Chapel Hill, United States
- Tikki Pang, Research Policy and Cooperation, World Health Organisation, Switzerland
- Ulysses Panisset, Research Policy and Cooperation, World Health Organisation, Switzerland

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**APPENDIX 2: QUESTIONNAIRE FOR UNITS PRODUCING CLINICAL PRACTICE GUIDELINES OR HEALTH TECHNOLOGY ASSESSMENTS**

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**Evidence-informed health policy:**

A critical review of organisations that support the use of research evidence in developing clinical practice guidelines and health policy

**Questionnaire for organisations producing clinical practice guidelines or health technology assessments**

Thank you for agreeing to complete this questionnaire.

We hope it will produce valuable information about how groups around the world use research evidence in developing clinical practise guidelines, health technology assessments and health policy.

Please do not hesitate to contact us at the following e-mail address if you have any questions about this project: [elizabeth.paulsen@kunnskapsenteret.no](mailto:elizabeth.paulsen@kunnskapsenteret.no)

This questionnaire is designed to be completed by units or departments that primarily produce clinical practice guidelines (CPGs), and/or produce health technology assessments (HTAs). If you primarily provide more direct support for developing health policy in other ways, please email Elizabeth Paulsen at the email address above to ask her to send you a different questionnaire.

First, can you give the name of your unit or department and provide a very simple description of its work. Please also provide a name, phone number, email and address of someone in your unit that can be contacted for additional information, in case we would like to follow up this survey with a telephone interview or site visit.

<b>Name of Unit:</b>
<b>Brief description of units work:</b>
<b>Name of person that can be contacted for additional information:</b>
<b>Phone:</b>
<b>Email:</b>
<b>Address:</b>

## ORGANISATION

1. Type of product
  - a. Clinical practice guidelines only
    - If yes, please answer all questions with this product in mind.
  - b. Health technology assessments only
    - If yes, please answer all questions with this product in mind
  - c. Both clinical practice guidelines and health technology assessments
    - If yes, please answer all questions with clinical practice guidelines in mind but, if your response would differ for health technology assessments, please indicate how it would differ in the margin to the right of the corresponding question.
  
2. Type of organisation
  - a. Academic institution
  - b. Disease specific association
  - c. Professional association (*e.g., medical specialty society*)
  - d. Biomedical or other for-profit company (*e.g., pharmaceutical company*)
  - e. Government agency →  Local  Regional  National
  - f. International agency
  - g. Other – *please specify*:
  
3. Year organisation began producing guidelines (or HTAs):  
\_\_\_\_\_
  
4. Source of funding for this activity (*please put an X next to all that apply*)
  - a. Biomedical or other for-profit company
  - b. Government
  - c. Other - *please specify*:
  
5. Estimated annual budget for this activity (in US dollars): \_\_\_\_\_
  
6. Estimated number of clinical practice guidelines (or HTAs) produced per year: \_\_\_\_\_
  
7. Estimated time for production of a single clinical practice guideline (or HTA): \_\_\_\_\_
  
8. What formal relationships does your unit have with government, universities, and other national and international organisations?
  
- 8a. Please describe in detail any relationships that are particularly important or valuable:
  
9. What are the main strengths of how your organisation is organised?

10. What are the main weaknesses of how your organisation is organised?

### WHY AND HOW THE ORGANISATION WAS ESTABLISHED

11. What background documents or resources were helpful in establishing your organisation?

12. Were examples from other countries helpful?

Yes → *Which examples?*

No

13. What other information would have been helpful in establishing the unit?

14. What advice would you give to others establishing a similar organisation?

### FOCUS

15. Domains from which topics are selected (*please put an X next to all that apply*)

a. Primary healthcare

b. Secondary healthcare

c. Tertiary healthcare

d. Public health (*i.e., public health is the objective of the policy*)

e. Healthy public policy (*e.g., economic, employment, housing or transport policies where the health of populations is a desired consequence of the policy but not necessarily a primary objective*)

16. Target users (*please put an X next to all that apply*)

a. Patients / public

b. Physicians

c. Other types of healthcare providers (*e.g., nurses*)

d. Healthcare managers (*e.g., hospital directors*)

e. Public policymakers (*e.g., civil servants in government*)

17. Involvement of target users in topic selection

a. Yes, by participation in priority-setting group

b. Yes, by survey of views / preferences

c. Yes, by review of draft list of priority topics

d. No

## PEOPLE INVOLVED IN GUIDELINE (OR HTA) DEVELOPMENT

18. Average number of members in a guideline (or HTA) development panel
- a. 1-5 Full time equivalents (FTE)  
 b. 6-10 (FTE)  
 c. 11-15 (FTE)  
 d. 16-20 (FTE)  
 e. >20 (FTE)
19. Involvement of experts/stakeholders in guideline (or HTA) development (*please put an X next to all that apply*)
- |                                       | Always involved          | Only if necessary        |
|---------------------------------------|--------------------------|--------------------------|
| a. Informatics / library science      | <input type="checkbox"/> | <input type="checkbox"/> |
| b. Clinical epidemiology              | <input type="checkbox"/> | <input type="checkbox"/> |
| c. Biostatistics                      | <input type="checkbox"/> | <input type="checkbox"/> |
| d. Health economics                   | <input type="checkbox"/> | <input type="checkbox"/> |
| e. Other types of social scientists   | <input type="checkbox"/> | <input type="checkbox"/> |
| f. Knowledge transfer / communication | <input type="checkbox"/> | <input type="checkbox"/> |
| g. Consumer                           | <input type="checkbox"/> | <input type="checkbox"/> |
| h. Other                              | <input type="checkbox"/> | <input type="checkbox"/> |
- please specify:*
20. Involvement of target users in guideline (or HTA) development
- a. Yes, by participation in development group  
 b. Yes, by survey of views / preferences  
 c. Yes, by review of draft guideline (or HTA)  
 d. No
21. Involvement of consumers (patients or representatives of the general public) in guideline (or HTA) development
- a. Yes, by participation in development group  
 b. Yes, by survey of views / preferences  
 c. Yes, by review of draft guideline (or HTA)  
 d. No
22. Criteria used explicitly in expert and/or target user selection (*please put an X next to all that apply*)
- a. Geographic balance  
 b. Gender balance  
 c. Other - *please specify:*

## METHODOLOGY OF GUIDELINE (OR HTA) DEVELOPMENT

23. Types of information provided to the panel (*please put an X next to all that apply*)
- a. Systematic reviews
  - b. Economic evaluations
  - c. Decision analyses
  - d. Existing burden of disease/illness
  - e. Existing practice patterns
  - f. Existing guidelines (or HTAs)
  - g. Resource constraints
  - h. Other - *please specify*:
24. Explicit valuation process (*please put an X next to all that apply*)
- a. Evidence is prioritized by its quality
  - b. Outcomes are prioritized by their importance to those affected
  - c. Groups are prioritized by their importance to achieving equity objectives
25. Methods used to formulate recommendations (*please put an X next to all that apply*)
- a. Subjective review
  - b. Informal consensus
  - c. Formal consensus (*e.g., consensus conference, nominal group technique, Delphi technique*)
  - d. Graded according to the quality of the evidence and/or the strength of the recommendation (using an explicit rating scheme)
26. Explicit assessment of (*please put an X next to all that apply*)
- a. The quality of evidence
  - b. Trade-offs between benefits and harms
  - c. Costs
  - d. Equity
27. Review process (*please put an X next to all that apply*)
- a. Clinical validation (*e.g., pilot testing, trial implementation period*)
  - b. Comparison with guidelines from other groups
  - c. Internal review
  - d. External review by experts
  - e. External review by target users
28. How does your organisation make decisions on which guidelines to develop, or technologies to assess?
29. What are the main strengths of the methods that you use?

30. What are the main weaknesses of the methods you use?

## PRODUCTS AND IMPLEMENTATION

31. Versions produced (*please put an X next to all that apply*)

- a. Full version with notes/references
- b. Executive summary
- c. Summary of take-home messages
- d. Separate summaries/versions for different target users
- e. Tools for application (*e.g., algorithms, flow charts*)

32. Does your unit send versions of its produces to the media as part of the dissemination/implementation strategy?

- a. Yes → *How?*
- b. No → *Why not?*

33. Implementation strategies used (*please put an X next to all that apply*)

- a. Mail or e-mail to target users
- b. Produce a CD-ROM and distribute it to target users
- c. Post to a website accessed by target users
- d. Submit to a guidelines (or HTA) clearinghouse
- e. Other - *please specify:*

34. Other implementation strategies used (*please put an X next to all that apply*)

- a. Patient-mediated interventions - *please specify:*
- b. Provider-mediated interventions (*e.g., audit and feedback*)  
- *please specify:*
- c. Organisational interventions (*e.g., change in setting of service delivery, coverage or reimbursement decision*) - *please specify:*

35. Strategies to develop the capacity of target users to acquire, assess and use clinical practice guidelines (or HTAs) (*please put an X next to all that apply*)

- a. Organise training workshops for target users
- b. Participate in training workshops for target users
- c. Develop a resource document for target users
- d. Other – *please specify:*

36. Involvement of target users in implementation

- a. Yes, by participation in implementation group
- b. Yes, by survey of views / preferences
- c. Yes, by review of draft implementation strategy
- d. No

37. What are the main strengths of the outputs of your organisation?

38. What are the main weaknesses of the outputs of your organisation?

### EVALUATION AND UPDATE PROCEDURES

39. Does your organisation collect data systematically about uptake?

- a. Yes
- b. No

40. Does your organisation systematically evaluate usefulness or impact in other ways?

- a. Yes – *please specify*:
- b. No

41. What does your organisation do to update guidelines (or HTAs)?

- a. Update regularly
- b. Updated irregularly
- c. Do not update

### ADDITIONAL QUESTIONS

42. Does your organisation also provide direct support to policymakers for developing health policy?

- a. Yes - *please specify*:
- b. No

43. Who are the strongest advocates of your organisation and why?

44. Who are the strongest critics of your organisation and why?

45. Please add any other comments you have about the strengths of your organisation with respect to how you support the use of research evidence in developing clinical practice guidelines or health technology assessments, including:

- a. Aspects of how you are organised or the methods that you use that you have found particularly useful
- b. Innovations in how you are organised or the methods that you use
- c. Examples of successes that you have had



46. Please also add comments about any additional information that this project might provide that you would like to have or that you believe would be helpful to other organisations like yours
  
47. What is your view about the current role the WHO, and other international organisations play in developing guidelines, recommendations, and helping policymakers to access and use research evidence?
  
48. What role do you think the WHO and other international organisations should play in developing guidelines, recommendations and helping policymakers to access and use research evidence?
  
49. Finally, are there other organisations like yours that you would suggest that we should include in our review?

Please feel free to describe some examples of the output of your unit:

**Thank you for participating in this survey!**

## **Evidence-informed health policy:**

A critical review of units that support the use of research evidence in developing clinical practice guidelines and health policy

### **Questionnaire for units supporting health policy**

Thank you for agreeing to complete this questionnaire.

We hope it will produce valuable information how groups around the world use research evidence in developing clinical practise guidelines, health technology assessments and health policy.

Please do not hesitate to contact us at the following email address, if you have any questions about this project: [elizabeth.paulsen@kunnskapsenteret.no](mailto:elizabeth.paulsen@kunnskapsenteret.no).

This questionnaire is designed to be completed by units or departments that primarily provide research evidence and other support for organisations or policymakers developing health policy. If your unit primarily produces clinical practice guidelines (CPGs), and/or produce health technology assessments (HTAs) please email Elizabeth Paulsen at the email address above, and ask for a different questionnaire.

First, can you give the name of your unit or department and provide a very simple description of its work. Please also provide a name, phone number, email and address of someone in your unit that can be contacted for additional information, in case we would like to follow up this survey with a telephone interview or site visit.

<b>Name of Unit:</b>
<b>Brief description of units work:</b>
<b>Name of person that can be contacted for additional information:</b>
<b>Phone:</b>
<b>Email:</b>
<b>Address:</b>

## ORGANISATION

1. Type of service undertaken in response to requests from public policymakers (*please put an X next to all that apply*)  
 a. Identify primary research  
 b. Identify systematic reviews of research  
 c. Identify clinical practice guidelines, HTAs or other prescriptive research-based documents  
 d. Undertake short-term research projects  
 e. Undertake systematic reviews of research  
 f. Commission systematic reviews of research  
 g. Convene expert meetings to discuss available research  
 h. Other – *please specify*:
  
2. Type of organisation  
 a. Academic institution  
 b. Disease specific association  
 c. Professional association (e.g., medical specialty society)  
 d. Biomedical or other for-profit company (e.g., pharmaceutical company)  
 e. Government agency →  Local  Regional  National  
 f. International agency  
 g. Other – *please specify*:
  
3. Year organisation began offering the service: \_\_\_\_\_
  
4. Source of funding for this activity (*please put an X next to all that apply*)  
 a. Biomedical or other for-profit company  
 b. Government  
 c. Other - *please specify*:
  
5. Estimated annual budget for this activity (in US dollars): \_\_\_\_\_
  
6. Estimated number of “services” produced per year (*please specify nature of service*): \_\_\_\_\_
  
7. Estimated time for production of a single “service”: \_\_\_\_\_
  
8. What formal relationships does your unit have with government, universities, and other national and international organisations?
  
- 8a. Please describe in detail any relationships that are particularly important or valuable:
  
  
9. What are the main strengths of how your organisation is organised?

10. What are the main weaknesses of how your organisation is organised?

### WHY AND HOW THE ORGANISATION WAS ESTABLISHED

11. What background documents or resources were helpful in establishing your organisation?

12. Were examples from other countries helpful?

\_\_\_ Yes → *Which examples?*

\_\_\_ No

13. What other information would have been helpful in establishing the unit?

14. What advice would you give to others establishing a similar organisation?

### FOCUS

15. Domains in which service can be provided (*please put an X next to all that apply*)

\_\_\_ a. Primary healthcare

\_\_\_ b. Secondary healthcare

\_\_\_ c. Tertiary healthcare

\_\_\_ d. Public health (*i.e., public health is the objective of the policy*)

\_\_\_ e. Healthy public policy (*e.g., economic, employment, housing or transport policies where the health of populations is a desired consequence of the policy but not necessarily a primary objective*)

16. Domains in which service can be provided (*please put an X next to all that apply*)

\_\_\_ a. Characterizing health problems

\_\_\_ b. Identifying potential solutions to health problems

\_\_\_ c. Fitting potential solutions into health systems (*e.g., governance, financial and delivery arrangements*)

\_\_\_ d. Bringing about change in health systems

17. Target users (*please put an X next to all that apply*)

\_\_\_ a. Public policymakers in health departments

\_\_\_ b. Public policymakers in other departments

\_\_\_ c. Public policymakers in central agencies (*e.g., executive branch*)

\_\_\_ d. Stakeholders

18. Involvement of target users in the services that you provide

\_\_\_ a. Yes, by participation in working groups

\_\_\_ b. Yes, by survey of views / preferences

\_\_\_ c. Yes, by review of draft reports

\_\_\_ d. No

19. Involvement of consumers (patients or representatives of the general public) in the services that you provide
- a. Yes, by participation in working groups
  - b. Yes, by survey of views / preferences
  - c. Yes, by review of draft reports
  - d. No

### PEOPLE INVOLVED IN SERVICE DELIVERY

20. Average number of staff involved in service delivery

- a. < 0.5 full-time equivalents (FTE)
- b. 0.5 – 1.9 FTE
- c. > 2 FTE

21. Involvement of experts/stakeholders in supporting the service (*please put an X next to all that apply*)

	Always involved	Only if necessary
a. Informatics / library science	<input type="checkbox"/>	<input type="checkbox"/>
b. Clinical epidemiology	<input type="checkbox"/>	<input type="checkbox"/>
c. Biostatistics	<input type="checkbox"/>	<input type="checkbox"/>
d. Health economics	<input type="checkbox"/>	<input type="checkbox"/>
e. Other types of social scientists	<input type="checkbox"/>	<input type="checkbox"/>
f. Knowledge transfer / communication	<input type="checkbox"/>	<input type="checkbox"/>
g. Consumer	<input type="checkbox"/>	<input type="checkbox"/>
h. Other	<input type="checkbox"/>	<input type="checkbox"/>
<i>please specify:</i>		

### METHODOLOGY OF RESPONSE DEVELOPMENT

22. Types of information employed (*please put an X next to all that apply*)

- a. Systematic reviews
- b. Economic evaluations
- c. Decision analyses
- d. Existing burden of disease/illness
- e. Existing practice patterns
- f. Existing guidelines (or HTAs)
- g. Resource constraints
- h. Commissioning of research
- i. Other - *please specify:*

23. Explicit valuation process (*please put an X next to all that apply*)

- a. Evidence is prioritized by its quality
- b. Outcomes are prioritized by their importance to those affected
- c. Groups are prioritized by their importance to achieving equity objectives

24. Methods used to formulate recommendations (*please put an X next to all that apply*)
- a. Subjective review
  - b. Informal consensus
  - c. Formal consensus (*e.g., consensus conference, nominal group technique, Delphi technique*)
  - d. Graded according to the quality of the evidence and/or the strength of the recommendation (using an explicit rating scheme)
25. Explicit assessment (*please put an X next to all that apply*)
- a. The quality of evidence
  - b. Trade-offs between benefits and harms
  - c. Costs
  - d. Equity
26. Review process (*please put an X next to all that apply*)
- a. Policy validation (*e.g., pilot testing, trial implementation period*)
  - b. Comparison with input from other groups
  - c. Internal review
  - d. External review by experts
  - e. External review by target users
27. How does your organisation make decisions on which topics to work on?
28. What are the main strengths of the methods that you use?
29. What are the main weaknesses of the methods that you use?

## **PRODUCTS AND IMPLEMENTATION**

30. Versions produced (*please put an X next to all that apply*)
- a. Full version with notes/references
  - b. Executive summary
  - c. Summary of take-home messages
  - d. Separate summaries/versions for different target users
  - e. Tools for application (*e.g., algorithms, flow charts*)
31. Does your unit send versions of its produces to the media as part of the dissemination/implementation strategy ?
- a. Yes → *How?*
  - b. No → *Why not?*
32. Implementation strategies used (*please put an X next to all that apply*)

- a. Mail or e-mail to target users
  - b. Produce a CD-ROM and distribute it to target users
  - c. Post to a website accessed by target users
  - d. Submit to a clearinghouse
  - e. Other - *please specify*:
33. Other implementation strategies used (*please put an X next to all that apply*)
- a. Patient-mediated interventions - *please specify*:
  - b. Provider-mediated interventions (*e.g., audit and feedback*)  
- *please specify*:
  - c. Organisational interventions (*e.g., change in setting of service delivery, coverage or reimbursement decision*) - *please specify*:
34. Strategies to develop the capacity of target users to acquire, assess and use re-  
search (*please put an X next to all that apply*)
- a. Organise training workshops for target users
  - b. Participate in training workshops for target users
  - c. Develop a resource document for target users
  - d. Other – *please specify*:
35. Involvement of target users in implementation
- a. Yes, by participation in implementation group
  - b. Yes, by survey of views / preferences
  - c. Yes, by review of draft implementation strategy
  - d. No
36. What are the main strengths of the outputs of your organisation?
37. What are the main weaknesses of the outputs of your organisation?

## EVALUATION AND UPDATE PROCEDURES

38. Does your organisation collect data systematically about uptake?
- a. Yes
  - b. No
39. Does your organisation systematically evaluate usefulness or impact in other  
ways?
- a. Yes - *please specify*:
  - b. No
40. Does your organisation update its products?
- a. Update regularly
  - b. Update irregularly
  - c. Do not update

## ADDITIONAL QUESTIONS

41. Other types of support for the use of research evidence
- a. Produce clinical practice guidelines
  - b. Produce HTAs
  - c. Other - *please specify*:
  - d. No
42. Who are the strongest advocates of your organisation and why?
43. Who are the strongest critics of your organisation and why?
44. Please add any other comments you have about the strengths of your organisation with respect to how you support the use of research evidence in developing clinical practice guidelines or health technology assessments, including:
- aspects of how you are organised or the methods that you use that you have found particularly useful
  - innovations in how you are organised or the methods that you use,
  - examples of successes that you have had
45. Please also add comments about any additional information that this project might provide that you would like to have or that you believe would be helpful to other organisations like yours.
46. What is your view about the current role the WHO, and other international organisations play in developing guidelines, recommendations, and helping policymakers to access and use research evidence?
47. What role do you think the WHO and other international organisations should play in developing guidelines, recommendations and helping policymakers to access and use research evidence?
48. Finally, are there other organisations like yours that you would suggest that we should include in our review?

Please feel free to describe some examples of the output of your unit:

**Thank you for participating in this survey!**

ID # \_\_\_\_\_



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## APPENDIX 4: INTERVIEW GUIDE FOR UNITS PARTICIPATING IN THE TELEPHONE INTERVIEWS

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ID Number

Name of Interviewee

Position

Name of Unit

Description of Unit

1. What are the most important informal relationships the unit has that help make its work more effective? (eg, relationships that operate nationally and internationally, with government, with academic institutions, professional groups, etc.)
2. What kind of staff does your unit have and how does this impact on the work you do?
3. To what extent does the unit commission work internally, externally?
4. What is the range of activities the unit is involved in, and what proportion of its resources goes to each: ie systematic reviews, HTAs, economic analysis, CPGs, preparing policy briefs and background documents for government, implementation and evaluation?
5. How are the priorities of the unit decided?
6. Can you describe in detail the methods your unit uses to produce the materials it produces? (i.e. steps to developing a systematic review or HTA of CPG or policy brief)
7. Does the unit have a manual describing the methods its uses?
8. Can you talk more about the strengths and weaknesses of the methods your unit uses?
9. To what extent does your unit use personal communications with decision-makers?
10. Who makes policy decisions or recommendations in connection with the outputs of your unit and what process do they use?
11. What are the main strengths and weaknesses of the way policy decisions or recommendations are made?
12. Who is responsible for implementing policy decisions or recommendations?
13. What are the main strengths and weaknesses of that implementation?
14. Can you tell us more about the strongest advocates for your unit, and what they say, and about the strongest critics of the unit and what they say? (Get contacts if haven't already.)
15. Can you give an example of a successful recommendation or decision that flowed from the work of your unit, and what made it successful?

16. Conversely, can you give an example of an unsuccessful recommendation or decision that flowed from the work of your unit, and what made it unsuccessful?
17. Can you talk more about advice you would give others trying to establish similar units? (Both positive advice and what pitfalls to avoid?)
18. Can you talk more about the strengths and weaknesses of how your unit is organised?
19. Follow up-questions - if needed - clarifying survey responses and asking any questions that may arise during interview.

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## APPENDIX 5: VIDEO DOCUMENTARIES

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Case study	Brief description	Length of the video (minutes)
Introduction	<a href="#">A short introduction to the eight case studies</a>	01:30
REACH Policy Initiative, East Africa	<a href="#">An initiative to create a multi-national unit that will act as a bridge between research and policy in the East African Community (comprising Kenya, Tanzania, and Uganda)</a>	08:26
Thailand	<a href="#">A constellation of research units that informed the development and evaluated the implementation of Thailand's nascent universal health insurance program, known popularly as the 30 Baht scheme</a>	07:46
Free State, South Africa	<a href="#">A set of long term relationships between provincial policy-makers and researchers and the tensions that can arise in these relationships</a>	09:55
Pharmaceutical Benefits Scheme, Australia & South Africa	<a href="#">An evidence-based drug assessment and pricing scheme in Australia and South Africa</a>	09:18
Philippines	<a href="#">An initiative to address conflicts of interest and inequity in the production of clinical practice guidelines</a>	09:01
Chile	<a href="#">An initiative to use clinical practice guidelines to make the best use of scarce resources</a>	07:48
National Institute of Clinical Excellence (NICE), United Kingdom	<a href="#">A unit producing guidelines and health technology assessments with a new focus on producing evidence-based public health guidelines to address health inequalities</a>	06:12
Mexico	<a href="#">A comprehensive effort to draw on research evidence to inform the development, implementation and evaluation of the new Popular Health Insurance scheme</a>	08:41

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## APPENDIX 6: LIST OF UNITS PARTICIPATING IN THE SURVEY AND TELEPHONE INTERVIEWS

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### Survey

#### *Organisations preparing CPGs*

- ACC/AHA Task Force on Practice Guidelines – United States
- ACCP thrombosis group, American College of Chest Physicians, Health and Science Policy – United States
- Agency for Quality in Medicine (AQuMed / AEZQ) – Germany
- Association of Scientific Medical Societies (AWMF) – Germany
- Bioethics and Evidence Based Medicine Unit, Ministry of Health – Chile
- Canadian Headache Society - Canada
- Cancer Care Ontario Practice Guidelines Initiative (Program in Evidence-Based Care) – Canada
- Centro de Investigación Epidemiológica en Salud Sexual y Reproductiva (CIESAR) – Guatemala
- Current Care /Duodecim (CC), Finnish Medical Society - Finland
- Dutch Association of Comprehensive Cancer Centres (ACCC) – Netherlands
- Dutch College of General Practitioners (NHG) – Netherlands
- Dutch Institute for Healthcare Improvement (CBO) – Netherlands
- Flemish College of General Practitioners (WVGH) – Belgium
- Frere and Cecilia Makiwane Hospitals, East London, Eastern Cape – South Africa
- Guidelines Project, Brazilian Medical Association and Federal Medicine Council - Brazil
- Hospital de la Sant Creu i Sant Pau, Iberoamerican Cochrane Centre – Spain
- Hospital Sirio Libanes – Brazil
- Institute for Quality in Healthcare (IQS) - Portugal
- National Board of Health and Welfare (SOS) – Sweden
- Norwegian Directorate for Health and Social Affairs (Shdir) - Norway
- Philippine Heart Association (PHA) - Philippines
- Philippine Obstetrics & Gynecology Society - Philippines
- Philippine Society for Microbiology & Infectious Diseases (PSMID) - Philippines
- Philippine Society of Gastroenterology - Philippines
- Projeto Diretrizes (Evidence Based Guidelines) – Brazil
- Royal College of Nursing Institute (RCN) – United Kingdom
- Scottish Intercollegiate Guidelines Network (SIGN) – United Kingdom
- Therapeutic Guidelines Limited (TGL) – Australia
- U.S. Department of Veterans Affairs, Office of quality and performance – United States
- United States Preventive Services Task Force (USPSTF) – United States
- Universidad Nacional de Córdoba- Facultad de Medicina – Argentina

#### *Organisations preparing HTAs*

- Alberta Heritage Foundation for Medical Research (AHFMR) – Canada
- Andalusian Agency for Health Technology Assessment (AETSA) – Spain
- Australian Safety and Efficacy Register of New Interventional Procedures, Surgical (ASERNIP-S) - Australia
- Canadian Coordinating Office for Health Technology Assessment (CCOHTA) - Canada

- Danish Center for Evaluation and Health Technology Assessment - Denmark
- Danish Institute for Health Services Research (DSI) - Denmark
- Finnish Office for Health Care Technology Assessment - Finland
- German Agency for Health Technology Assessment - Germany
- Institute of Applied Health Sciences (IAHS) – United Kingdom
- Institute of Technology Assessment (ITA) – Austria
- Instituto de Salud Carlos III (AETS) – Spain
- Israeli Center for Technology Assessment in Health Care (ICTAHC) - Israel
- Key Lab of Health Technology Assessment, Ministry of Health – China
- New Zealand Health Technology Assessment (NZHTA) – New Zealand
- NHS Health Technology Assessment Programme (NCCHTA), Wessex Institute for Health Research – United Kingdom
- NHS Quality Improvement Scotland (NHS QIS) – United Kingdom
- Norwegian Knowledge Centre for the Health Services - Norway
- Ontario Ministry of Health and Long term care, Medical Advisory Secretariat - Canada
- Swedish Council on Technology Assessment in Health Care (SBU) - Sweden

***Organisations preparing both CPGs and HTAs***

- Academia Nacional de medicina - Argentina
- Agency for Healthcare Research and Quality (AHRQ) – United States
- All India Institute of Hygiene & Public Health, Department of Epidemiology - India
- American Cancer Society – United States
- Armenian Scientific Centre of Drug and Medical Technology Expertise - Armenia
- Basque Office for Health Technology Assessment (OSTEBA) - Spain
- Bazian – United Kingdom
- BC Therapeutics Initiative - Canada
- Belgian Health Care Knowledge Centre (KCE) - Belgium
- Bureau of Medical Technology Development - Thailand
- Catalan Agency for Health Technology Assessment and Research (CAHTA) - Spain
- Centre for Reviews & Dissemination (CRD) – United Kingdom
- CIGES. Universidad de la Frontera - Chile
- Clinical Epidemiology Centre (CePic), University Hospital Lausanne - Switzerland
- Departamento Tecnico Normativo de Regulacion Sanitaria Secretaria de Salud - Honduras
- Department of Clinical Epidemiology, College of Medicine, University of the Philippines – Philippines
- Department of Science and Technology (DECIT), General-Coordination of Research Support and Technological Development - Brazil
- ECRI – United States
- EPPI Centre, Social Science Research Unit, Institute of Education – United Kingdom
- Federal Joint Committee (GBA) - Germany
- French National Health Authority (HAS) - formerly ANAES - France
- Fundación Salud, Ambiente y Desarrollo (FUNDSAD) - Ecuador
- Guide for Community Preventive Services, CDC – United States
- Health Evidence Network (HEN) – WHO European Region
- Joanna Briggs Institute (JBI) - Australia
- Josep Laporte Library Foundation - Spain
- Knowledge Translation Unit, University of Cape Town Lung Institute – South Africa

- L'Agence d'évaluation des technologies et des modes d'intervention en santé (AETMIS) - Canada
- Medical Information Network Distribution Service (MINDS), Department of R & D, Japan Council of Quality Health Care (JCQHC) - Japan
- Medicines Pricing and Reimbursement Agency - Latvia
- National Center for Health Development, Ministry of Health - Mongolia
- National Federation of Cancer Centres (FNCLCC) - France
- National Health and Medical Research Council (NHMRC) - Health Advisory Committee (HAC) - Australia
- New Zealand Accident Compensation Corporation (ACC) - New Zealand
- New Zealand Guidelines Group (NZGG) - New Zealand
- NICE - United Kingdom
- Philippine College of Chest Physicians - Philippines
- Philippine Health Insurance Corporation (PhilHealth) - Philippines
- Philippine Pediatric Society - Philippines
- Evidence Based Guidelines, National Program, National Social Security bureau, Costa Rica Health Care delivery system - Costa Rica
- Royal Dutch Society for Physical Therapy (KNGF) - Netherlands
- U.S. Multi-Society Task Force on Colorectal Cancer - United States
- UETS - Spain
- VA Technology Assessment Program (VA TAP) - United States
- World Health Organization, Essential drugs and medicine department (EDM) - International

### ***GSU organisations***

- BC PharmaCare - Canada
- Brazilian Cochrane Centre - Brazil
- Caribbean Food and Nutrition Institute (CFNI) - Jamaica
- Center for Health Management & Policy, Shandong University - China
- Center for Health Policy Research and Development - Taiwan
- Centre for Health Policy, School of Public Health, University of the Witwatersrand - South Africa
- Chinese Cochrane Centre, Hong Kong Branch - China
- Chinese Evidence Based Medicine Centre, Ministry of Health - Chinese Cochrane Centre - Virtual Research Center of EBM - China
- Clinical Trial Unit (CTU)/Jordan Food and Drug Administration (JFDA) - Jordan
- COHRED - International
- College voor zorgverzekeringen (CVZ), Health Care Insurance Board - Netherlands
- Colombian Health Association (ASSALUD) - Colombia
- Community Drug Utilization Program - Canada
- Coverage and Analysis Group, Centers for Medicare and Medicaid Services (CMS) - United States
- Curatio International Foundation - Georgia
- Department of Public Health and Health Management - Uzbekistan
- Drug Effectiveness Review Project - United States
- European Observatory on Health Systems and Policies - Belgium
- Guidelines Advisory Committee (GAC) - Canada
- Health Policy Analysis Project - Kyrgyzstan

- Health Policy Research Group, Centre for Health Policy (at the MRC) – South Africa
- Health Services Development Unit, The University of the Free State, Centre for Health Systems Research and Development – South Africa
- Health Systems Research Institute - Thailand
- Health Systems Trust – South Africa
- Health Technology Inquiry Service (HTIS), at Canadian Coordinating Office for Health Technology Assessment (CCOHTA) - Canada
- HEARTFILE - Pakistan
- INCLIN - International
- Indian Council of Medical Research - India
- Institute for Clinical Evaluative Sciences (ICES) - Canada
- Institute for Health Policy / Health Policy Research Associates – Sri Lanka
- Institute for Health Research, Lancaster University – United Kingdom
- Institute for Health Systems Research - Malaysia
- Institute of Public Health in Ireland - Ireland
- Instituto de Efectividad Clínica y Sanitaria (IECS), School of Medicine - Argentina
- Instituto de Investigación Nutricional - Peru
- Instituto Mexicano de Seguro Social (IMSS) - Mexico
- International Health Policy Program - Thailand
- Iran Drug Selection Committee, in Ministry of health - Iran
- Karolinska Institute, with collaborative relationship with the Laos Ministry of Health - Sweden
- Ministry of Health - Mexico
- MRC, University of Glasgow – United Kingdom
- National Institute of Health Research and Development - Indonesia
- Nepal Health Research Council - Nepal
- Pharmaceutical Benefits Advisory Committee (PBAC) - Australia
- Population Council para América Latina y el Caribe - Mexico
- RAND – United States
- Regional Health Agency Emilia Romagna (ASR) - Italy
- Research Promotion Office, Faculty of Medicine, Siriraj Hospital - Thailand
- Rhofo Finland, national drug rationalisation agency - Finland
- Swiss Centre for International Health - Switzerland
- ThaiHealth Foundation - Thailand
- The Directorate of Training and Planning, The Ministry of Health - Bahrain
- The Sax Institute - Australia
- University of Cape Town, Public Health Programme – South Africa
- Universidad del Cauca (CAU), Clinical Epidemiology Unit - Colombia
- University of Tucuman (UTUC) - Argentina
- ZdravPlus Project - Kazakhstan

## Telephone interviews

<i>Organisation, Country</i>	<i>Region</i>	<i>Type</i>
1. Therapeutics Initiative, British Columbia, Canada	NA	CPG/HTA
2. Institute for Quality in Healthcare (IQS), Portugal	WE	CPG
3. Scottish Intercollegiate Guidelines Network (SIGN), Scotland	WE	CPG
4. Canadian Coordinating Office for Health Technology Assessment Health Technology Inquiry Service (HTIS), Canada	NA	GSU (CCOHTA),
5. Iran Drug Selecting Committee, Ministry of Health, Iran	ME	GSU
6. Joanna Briggs Institute (JBI), Australia	AN	CPG/HTA
7. Ontario Ministry of Health and Long Term Care, Medical Advisory Secretariat, Ontario, Canada	NA	HTA
8. Guide for Community Preventive Services, Centers for Disease Control and Prevention (CDC), USA	NA	CPG/HTA
9. Drug Effectiveness Review Project, Center for Evidence Based Policy, USA	NA	GSU
10. Projeto Diretrizes (Evidence Based Guidelines, Brazil	LA	CPG
11. French National Health Authority (HAS, formerly ANAES)	WE	CPG/HTA
12. International Health Policy Program, Ministry of Health, Thailand	AS	GSU
13. University of Cape Town Economics Unit, South Africa	AF	GSU
14. Israeli Center for Technology Assessment in Health Care (ICTAHC), Israel	ME	HTA
15. Ministry of Health, Mexico	LA	GSU
16. Bazian Ltd., UK	WE	CPG/HTA
17. Medicines Pricing and Reimbursement Agency, Latvia	EE	GSU
18. Institute for Health Systems Research, Malaysia	AS	GSU
19. Curatio International Foundation, Georgia	EE	GSU
20. Bioethics and Evidence Based Medicine Unit, Ministerio de Salud, Gobierno de Chile	LA	CPG
21. Medical Research Council (MRC) Social and Public Health Sciences, University of Glasgow, Scotland	WE	GSU
22. Finnish Office for Health Technology Assessment (FINOHTA), Finland	WE	HTA
23. Philippines Heart Association, Philippines	AS	CPG
24. Health Systems research Institute, Thailand	AS	GSU
25. Center for Health Systems Research and Development, University of the Free State, South Africa	AF	GSU